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Care, support and HIV support groups in Nairobi, Kenya

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2017

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Citation for published version (APA):

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My Brother's Keeper?

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Care, Support and HIV support groups in Nairobi, Kenya

Emmy Kageha Igonya



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My brother's keeper?

Care, support and HIV support groups in Nairobi, Kenya

ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad van doctor

aan de Universiteit van Amsterdam

op gezag van de Rector Magnificus

prof. dr. ir. K.I.J. Maex

ten overstaan van een door het College voor Promoties ingestelde
commissie, in het openbaar te verdedigen in de Aula

op woensdag 4 oktober 2017 te 13 uur

door Emmy Kageha Igonya

geboren te Vihiga, Kenia

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The research for this thesis received funding from the Dutch Scientific Council (NWO)

Cover Design by: Caroline Kamau

TABLE OF CONTENTS

| | |
|--|-------|
| TABLE OF CONTENTS | iiiiv |
| INDEX OF ABBREVIATIONS AND ACRONYMS | viii |
| GENERAL INTRODUCTION | 1 |
| Support group: from a 'school of life' to being 'dumped like a toilet paper' | 1 |
| HIV and AIDS response in Kenya | 4 |
| Studying HIV support groups in Kenya | 5 |
| Comparing models of support groups in time and space | 8 |
| Study site | 11 |
| Nairobi | 12 |
| Outline of the thesis | 19 |
| CHAPTER 1 | 21 |
| METHODOLOGICAL ISSUES | 21 |
| Apprehending the fragmented object of HIV support groups in Nairobi | 21 |
| The changing tides of HIV research | 21 |
| Reflecting on class and the need for contrasting case studies | 23 |
| Mapping the (un)mapable: ethnography as a methodological approach | 25 |
| Data sources and collection | 35 |
| Key informant interviews | 36 |
| Participant observation | 38 |
| Conversations | 40 |
| In-depth interviews | 41 |
| Walking sessions | 42 |
| Focus group discussions | 43 |
| Life histories | 44 |
| Media review | 44 |
| Ethical clearance and social license | 45 |

| | |
|---|-----------|
| Protected space and staying longer | 45 |
| 'What have you brought for us?' Expectations of assistance and recompense | 46 |
| Money matters within support groups | 49 |
| Being legal in an 'illegal' space: working with MSM male sex workers | 50 |
| Researching sensitive issues | 52 |
| Conclusion | 56 |
| CHAPTER 2 | 58 |
| THEORIZING COLLECTIVE CARE AND SUPPORT | 58 |
| Background | 58 |
| Previous research with support groups | 61 |
| Defining care and support | 64 |
| 'Support' as a component of care | 66 |
| Support as 'walking together' | 67 |
| 'Support' as msaada | 68 |
| 'Support' as 'my brother's keeper' | 69 |
| From support to support groups | 70 |
| HIV and the rise of support groups | 73 |
| Social science and HIV support groups | 76 |
| Social relations and HIV: a theoretical perspective | 79 |
| CHAPTER 3 | 83 |
| HIV SUPPORT GROUPS IN HISTORICAL PERSPECTIVE | 83 |
| Introduction | 83 |
| The failed state and societal responsibility | 84 |
| Emergence of the Know AIDS Society (KAS) in Nairobi | 88 |
| Emergence of HIV support groups in Kibera | 90 |
| Emergence of HIV support groups in upper and middle class | 91 |
| From victims to HIV moguls: inclusions, exclusions, and diversification | 93 |

| | |
|---|------------|
| External influence | 95 |
| The scramble for funding | 99 |
| Conclusion | 105 |
| CHAPTER 4 | 107 |
| TREATMENT ERA: A TIME OF SUPPORT GROUPS' PROLIFERATION AND DECLINE | 107 |
| Introduction | 107 |
| National disaster and response (late 1999–2002) | 108 |
| From post-test clubs to support groups, | 109 |
| Materialization of support groups in Kibera | 112 |
| A time of resurrection (2003–2008) | 113 |
| Growth of a local economy of NGO/CBOs | 113 |
| Medicalization and msaada at KNH | 116 |
| HIV treatment and msaada in Kibera | 118 |
| Beyond HIV crisis: New strategies, new populations | 122 |
| New strategies and support groups in Kibera | 124 |
| Hyper-medicalization of support groups at KNH | 124 |
| Resilience and redundancy of community-based institutions and skills | 131 |
| Conclusion | 133 |
| CHAPTER 5 | 135 |
| WHEN FAMILIES FAIL: SHIFTING EXPECTATIONS OF CARE AMONG PEOPLE LIVING WITH HIV IN NAIROBI, KENYA | 135 |
| Abstract | 136 |
| Introduction | 137 |
| The right to care | 140 |
| Methodology | 141 |
| Shifting configurations of care | 142 |
| Provisional responses in precarious contexts | 143 |

| | |
|--|------------|
| Care and support in the city prior to antiretroviral treatment Care | 144 |
| and support in the age antiretroviral treatment and msaada Care | 146 |
| and support needs in the wake of crisis | 148 |
| Conclusion | 151 |
| CHAPTER 6 | 153 |
| PUTTING SEX ON THE TABLE: SEX, SEXUALITY, AND MASCULINITY AMONG HIV-POSITIVE MEN IN NAIROBI, KENYA | 153 |
| Abstract | 154 |
| Introduction | 155 |
| Background | 157 |
| Methodology | 158 |
| Ethical considerations | 160 |
| Sexuality and masculinity in Africa in times of HIV | 160 |
| HIV support groups in Kenya | 162 |
| Sex therapy for HIV-positive men | 162 |
| “It is better to be born impotent...” | 164 |
| The problem with condoms Sexual | 166 |
| gratification and fertility The | 168 |
| limits of group therapy | 168 |
| Conclusion | 170 |
| CHAPTER 7 | 172 |
| MY BROTHER’S KEEPER: CARE AND SUPPORT AMONG MALE SEX WORKERS | 172 |
| Introduction | 172 |
| Homosexuality, sex work, discrimination, and the law | 173 |
| Freedom Corner: redefining HIV and AIDS care and support | 177 |
| Reflecting on conversations and gossip at Freedom Corner | 186 |
| Sex, sex work, clients, and pleasure | 187 |

| | |
|--|------------|
| Emotionally wounded: (psycho)sociological | 194 |
| issues Homosexuality, masculinity, and | 200 |
| fatherhood Conclusion | 202 |
| CHAPTER 8 | 205 |
| CONCLUSION: You do not understand! | 205 |
| Implications of HIV support groups for PLHIV | 211 |
| Psychological and emotional | 212 |
| reprieve Information and health | 213 |
| implications Economic/material | 214 |
| implications Social implications | 214 |
| Social support implications | 215 |
| | 215 |
| Limitations of support | 217 |
| groups Conclusion | 219 |
| REFERENCES | |
| SUMMARY | 241 |

Acknowledgements

Writing this thesis brought about a lot of memories and reflections of academic journey, friendships and relationships as well as pain and joys. I am indebted to a number of people who supported me during my PhD journey.

First and foremost, with gratitude, I am indebted to the men and women living with HIV who let me into their support group space and private lives. We had times of great joys as well as times of pain. Thank you for inviting me to your activities including walking sessions, weddings and visiting those who got babies: and advocacy- we laughed and friendships that grew and developed in different directions. I will always cherish these moments. I wish to acknowledge the men in an exclusive male therapy group and freedom corner group who overlooked cultural norms to share with me their sexual lives.

Many thanks to my key informants who opened their doors for me to walk in as many times, through face-to-face meetings or phone call discussions. Your contribution and your unwavering support in this journey is deeply appreciated. I acknowledge Prof. Alloys Orago, Joe Muriuki, Allan Ragi, Dr. David Bukusi, Kenyatta National Hospital peer mentors, National HIV NGO's Chef Executive Officers and staff, and staff of International development partners.

I acknowledge and appreciate the Dutch Scientific Council (NWO) for funding the research for this thesis. Thank you.

My deepest heartfelt gratitude is reserved for my promoter Prof. Anita Hardon, and co-promoters Ass. Prof. Eileen Moyer and Prof. Octavian Gakuru. Being supervised by Prof. Anita was an honour. Thank you for walking with me through this journey. I am humbled. You read through several drafts and provided much appreciated feedback. Thank you for

directions, insights and a wonderful working relation. Thank you for humour in your serious feedback. Ass. Prof. Moyer, I am considerably bound in words to express your significant place in this journey. You have been more than a supervisor, a mentor and a friend. This thesis would not have been possible without your insights, guidance, encouragement and boundless patience. I have learnt a lot from you including humility, kindness and caring for others, and balancing between friendship and professionalism. When I felt discouraged, those values made me smile and move on with the journey. Thank you for being the light in this journey. I will forever be grateful for mentorship and generosity. *Ahsante sana dada. Shukrani kwa kazi njema.*

I extend my deepest appreciation to Prof. Octavian for generously sharing his time and expertise. I was deeply touched as you shared with me and your masters students at the university of Nairobi how, during the difficult time of your illness, on a hospital bed you felt you would have left me down if you didn't make it to my defence. These were not only the words of a supervisor but of a father I missed for long. Even as you are not able to be at the University of Amsterdam, I am glad you join in the celebration. Thank so much Prof.

My parents- the late Hezekiah and Jesicah Igonya, I pen down with great pain and joy. Pain because you left too early, and not here to witness the journey you started for me. Joy for the short, beautiful moments we shared. Thank you for being my first teachers. Thank you for the values that have kept me going. Mum, thank you for teaching me about kindness, caring for others and humility. These virtues have been handy in my relationships and research profession. Dad, thank you for the light moments and the discipline.

To my brothers, sisters and in- laws, you made me realize that the PhD was not only for me, but for all of you. The phrase '*you have made us proud*' was where I anchored my motivation to finish the race. As a family, during this journey we shared great joys and the most difficult moments. These moments gave me purpose and made me stronger. Thank you

Iris, George, Everlyne, Allan, Harold, John, Doris, and Dan for holding together. With tears of pain and joy I am especially indebted to my late sister Grace and brother in-law Ben Makindu; you were the greatest support ever, unfortunately you left a year into the journey. I will forever be grateful to your imprints on this journey.

My children and spouse deserve special thanks, not only for their love and unwavering emotional support but also their understanding. I owe special thanks to my husband Ignatius Jajo Mukobi. While I was still contemplating whether or not to take up the PhD position, without wavering you told me to accept the position. I would have been a fool not to accept it. Indeed you proved yourself through your unwavering support throughout this journey as you became the famous '*father of girls*'. Without your love, encouragement, and support, the journey would have been tough. Together with the children, the most memorable moments were your reflections on the joy and difficulties of your lives during my absence. Thank you: Benah, Kristie, Mariah, Michael, Ivy, Gail, Ian and Shakinah. You made me to keep walking the journey. To my house assistant Emily, you are much appreciated.

Thanks are also due to my friends and former colleagues in Kenya who after sharing with them about going back to school for PhD, they enrolled for bachelors and masters' degrees while some expressed their desires to enrol for PhDs. The truth is that I was looking forward to your discouragement. I was wrong. Only one of you thought I was out of my mind to go back to school. Two years later she also was out of her mind to enrol for a PhD in a Kenyan University. Your motivational part in this journey is much appreciated. I am happy that this PhD left a mark on your academic lives.

Much appreciated is the support from University of Amsterdam colleagues and staff. I wish to acknowledge my colleagues Nipael Mrutu (Tanzania) and Joseph Simbaya (Zambia) and Josien de Klerk (The Netherlands) for their encouragement and company that made life in Amsterdam so manageable. Similarly, I thank Rosalijn Both and her family (Dad, Mum

and siblings) - my family in the Netherlands. Collectively, I wish to thank those who participated in the reading and writing groups. You know your part in this journey.

Much appreciated are the Amsterdam Institute for Social Sciences Research (AISSR) staff and project administrators: Kiesel Muriel, Jose Komen, Yomi van der Veen, Hermance Mettrop, Nicole Schulp, Janus Oomen, Joanne Oakes, Teun Bijvoet, Eva Wulp and the support staff.

Last but not least, I wish to acknowledge my paranymphs: Dr. Gavaza Maluleke and Katlego Disemelo. Thank you.

Above all, I am thankful to God.

Emmy Kageha Igonya,

Nairobi, Kenya

October, 2017

Dedication

This thesis is dedicated to the memory of

my father Hezekiah Igonya & my mother Jescah Igonya whose treasure memories of wanting
their children to be educated hold so many untold stories

with joys, my sister Grace Igonya who couldn't see me through a journey she encouraged me
to take

with love to Fabian Wangare, my PhD study participant who I couldn't save

Also

with loves and joys to my husband and children, you are special.

INDEX OF ABBREVIATIONS AND ACRONYMS

| | |
|----------|--|
| AED | Academy for Educational Development |
| AIDS | acquired immune deficiency syndrome |
| AMREF | Africa Medical Relief and Emergency Foundation Health Africa |
| ART | antiretroviral treatment |
| ARV | antiretroviral |
| CBO | community-based organization |
| CDC | Centers for Disease Control and Prevention |
| CD4 | T-cell count |
| CHAK | Christian Health Association |
| EATAM | East Africa Treatment Movement |
| EDARP | Eastern Deanery AIDS Relief Program |
| FGD | focus group discussion |
| FOPHAK | Foundation of PLWA in Kenya |
| GIPA | Greater Involvement of People with AIDS |
| GNP+ | Global Network of People Living with HIV |
| HIV | human immunodeficiency virus |
| HOYMAS | Health Options for Young Men with AIDS and STI |
| ITPC | International Treatment Preparedness Campaign |
| KAIS | Kenya AIDS indicator survey |
| KAS | Know AIDS Society |
| KDHS | Kenya Demographic Health Surveys |
| KANCO | Kenya AIDS National Consortium |
| KETAM | Kenya Treatment Access Movement |
| KHADRE | Kenyan HIV and AIDS Disaster Response |
| KICOSHEP | Kibera community self-help programme |
| KIPOTEC | Kibera post-test clubs |
| KNH | Kenyatta National Hospital |
| KNASP | Kenya national AIDS strategic plan |
| KRC | Kenya Red Cross |
| LGBTI | lesbian, gay, bisexual, transgender, intersex |
| MMAK | Movement of Men against AIDS in Kenya |

| | |
|----------|--|
| MDG | Millennium Development Goal |
| MIPA | meaningful involvement of people with AIDS |
| MSF | Médecins San Frontières |
| MSM | men who have sex with men |
| MSMSW | men who have sex with men sex workers |
| NACC | National AIDS Control Council |
| NASCOP | National AIDS/STI Control Programme |
| NCCK | National Council of Churches of Kenya |
| NEPHAK | Network of People Living with AIDS in Kenya |
| NNEPOTEC | Nairobi Network of Post-Test Clubs of People Living with HIV/AIDS in Kenya |
| NGO | nongovernmental organization |
| OVC | orphans and vulnerable children |
| PATH | Program for Appropriate Technology in Health |
| PEPFAR | US President's Emergency Plan for AIDS Relief |
| PLWA | people living with AIDS |
| PLHIV | people living with HIV |
| PMTCT | prevention of mother-to-child transmission of HIV |
| PTC | post-test club |
| TAPWAK | The Association of People with AIDS in Kenya |
| TASO | The AIDS support organization |
| TOWA | total war against AIDS |
| UNCEF | United Nations Children's Fund |
| UNDP | United Nations Development Programme |
| UNAIDS | The Joint United Nations Programme on HIV/AIDS |
| VCT | voluntary counselling and testing |
| WHO | World Health Organization |

GENERAL INTRODUCTION

Support group: from a 'school of life' to being 'dumped like a toilet paper'

People with HIV can play an important role in their own care through self-help groups. Being passive, dependent and feeling helpless lowers self-esteem and easily leads to depression. Self-help includes looking after one's own physical health and wellbeing and seeking emotional support and practical ideas from others, such as by joining support groups. (Jackson, 2002, p. 213)

Near the beginning of my field research on human immunodeficiency virus (HIV) support groups in Nairobi, I met Joseph Jalang'o at the Nairobi commemoration of the International AIDS Candlelight Memorial, an annual event organized every May by The Association of People with AIDS in Kenya (TAPWAK), a pioneer HIV and AIDS nongovernmental organization in Kenya. Joseph, a 47-year-old father of four living with HIV, had been involved with four different HIV support groups since his diagnosis. In addition to representing his current organization at the event, Joseph was in charge of mobilizing HIV support groups from the Eastlands area of Nairobi. In the course of our small talk, Joseph emphasized, 'The support group is a school of life – just sharing experiences with other people infected with HIV gave me back my life'. Given his positive outlook on support groups when we first met, I was taken by surprise during our second meeting when he remarked, 'Support groups can be disappointing. ... I think I got involved in HIV activities by mistake. ... I have been used and dumped like toilet paper!' His change in attitude was both striking and intriguing, but most importantly it alerted me to the complex and contradictory attitudes that people may hold about support, care, and HIV support groups.

As I came to know more about Joseph over time, I learnt more about the torments of his memory, which took him back to the time around his HIV positive diagnosis. I also learnt that since that time, he had been moving from one support group to another, not only so to satisfy his ever-changing needs and expectations but also because the goals of the support groups themselves had transformed over time. Joseph learned he was HIV positive in 1992 when a doctor advised him to test in an attempt to explain his recurrent illnesses and frequent hospitalizations. His wife had passed on

some time earlier – from AIDS, as he would learn later – and he had lost his job as a result of frequent sickness. These setbacks devastated Joseph and, in his quest for help, he had joined his first HIV support group. According to him, joining this group was a godsend. In addition to improving his knowledge of HIV and AIDS, Joseph benefitted greatly from the sharing of experiences and learning about coping mechanisms from his fellow people living with HIV (PLHIV). Joseph says he learned how to ‘live positively with HIV’¹ and that soon his dire situation became manageable. His participation in the support group brought him opportunities to earn money through HIV advocacy and awareness-raising activities, which helped him to take care of his family and himself. This initial support group experience raised his expectations and desires for further opportunities. All this was shattered, however, when the support group disintegrated due to alleged corrupt practices including the mismanagement of funds by the support group leaders. He could no longer secure paid advocacy opportunities.

The next support group that he joined was run by a nongovernmental organization (NGO). It exposed Joseph to similar services and opportunities at first, supporting him in his struggle against HIV and even sponsoring him to attend HIV and AIDS conferences to both learn and to share his experiences. However, with the death of the NGO’s director, support from the NGO failed and once again Joseph lost access to the economic, social, and psychological support vital to managing his health. A third support group only provided unpaid volunteer work and could certainly not meet his economic needs, leading Joseph to turn to garden landscaping for income, work he had done before getting sick. Much later, Joseph joined a fourth support group – the one where I met him – that offered supportive counselling. After much effort, the members convinced Joseph to enrol in an antiretroviral treatment (ART) program, something he was hesitant to do despite his failing health and the fact that he was surrounded by people already on treatment.

One of the most profound social transformations brought about by HIV has been the emergence of HIV support groups, most of which are led by PLHIV. Over the last

¹ ‘Living positively’ is a shorthand used by many activists, and it encompasses a range of behaviours that include protecting oneself from re-infection by using condoms during sex; eating a healthy diet and taking immune boosters/supplements to support your immune system; avoiding alcohol, drugs, and stress; and exercising. This set of behaviors was learned in the context of HIV support groups throughout Kenya and much of the world and can be traced back to early AIDS patient activism in the West.

three decades, support groups have emerged as new social forms and institutions, and a key site of HIV biosocialization around the world, serving as important platforms for care and support. In Kenya, the care and support needs of people with HIV quickly outpaced existing health and kinship support systems. In this thesis, I trace the how HIV support groups emerged, expanded, contracted, and transformed over the last three decades to fill gaps in existing care systems. Support groups emerged sporadically, but had significant influence in the early years of AIDS; many people with AIDS had lost their incomes, experienced high levels of stigma and discrimination, and were rejected or isolated by families and communities, resulting in a care crisis. For those living with AIDS in the years prior to antiretroviral treatment, the groups became important substitutes for forms of care and support that might have been offered by both the national health system and kin had they been better prepared to do so.

Joseph's story offers insight into the range of relationships and meanings PLHIV have with support groups. It exemplifies many of the issues associated with the rise of support groups in the crisis and treatment of HIV and AIDS in Kenya, the expectations that people have of such groups, and the potential of support groups to help people to battle against the disease and manage HIV. In situations of hopelessness and desperation, locally based support groups may offer hope through the sharing of experiences and knowledge about HIV, providing nursing care (where needed), as well as psychosocial and occasional economic support. In the context of international development, many international actors in the HIV prevention and treatment domain have also turned to support groups to advance human rights and promote effective HIV behavioural and biomedical interventions. This engagement between local support groups and international donors has expanded the functions of these groups, altering their objectives, organizational characteristics, leadership, and methodologies. Because support groups are usually dependent on international donors for funding, the services they offer are very often fragmented and sporadic. Support groups are forced to continuously shift goals, activities, and partnerships in tandem with the shifting priorities in the global HIV terrain, as well as the shifting needs, challenges, and expectations of each group. For it is not just the global actors who are continuously engaging and disengaging in specific programs; the group's members and program organizers come and go as well. In spite of this fragmentation, however, support groups continue to help PLHIV access care and treatment, thus remaking the lives of PLHIV.

In this study I examine how HIV transforms care and social support systems. Specifically, I examine relationships between individual support group members and the HIV support group structure in Kenya, exploring how social relations are created, shaped, and redefined around HIV-positive status in Nairobi, Kenya. I argue that support groups are spaces where the interests of individuals with HIV intersect with those of development partners and biomedical interventions. Given this, I ask why, how, and by whose hand did support groups emerge, and what is it that they actually do? How are support groups imagined, utilized, and reworked by differently positioned actors to meet the shifting care and support needs of PLHIV over time?

HIV and AIDS response in Kenya

Kenya is infamous for its late recognition of the HIV epidemic following the first reported case in 1984 (Muraah & Kiarie, 2001). Between 1984 and late 1999 when HIV was finally declared a national disaster by President Daniel Arap Moi, the government of Kenya failed in its responsibility to protect the health of its citizens. However, since the early 2000s Kenya has stepped up its response, and is today heralded for its concerted efforts in the fight against HIV. The many HIV interventions Kenya has adopted and rolled out over the last 15 years show the seriousness with which the state is committed to dealing with HIV. The country has positioned itself as a pacesetter in adopting aggressive interventions such as medical male circumcision, provider-initiated testing and counselling and key populations in addition to other interventions.

Since 2006 especially, somewhat impressive results have been noted. There has been a decrease in HIV- and AIDS-related mortality and morbidity, an increase in uptake of HIV testing and counselling, greater availability of and access to HIV treatment and prevention of mother-to-child transmission (PMTCT) services, and an impressive male circumcision (National AIDS & STI Control Programme (NAS COP), 2013; Kenya National Bureau of Statistics² (KNBS), 2008/9). According to the 2012 Kenya AIDS Indicator Survey (KAIS) report, 53 per cent of the 1.6 million people projected to be HIV positive status knew about their HIV status and 63 per cent of those aware of their HIV status were receiving HIV treatment by 2012. An increase in uptake of HIV testing among adults was reported, from 37 per cent in 2007 to 72 per cent in 2012 (NAS COP, 2013).

² Former central bureau of statistics (CBS), Kenya

The crisis framing of AIDS may be coming to an end in Kenya and elsewhere in Africa. Despite the positive reports and evident successes, however, Kenya is not yet out of the woods. With one of the highest – though relatively stable – rates of HIV (5.6 per cent) in sub-Saharan Africa (NASCO, 2013), stigma, poverty, and the devastating effects of HIV persist into the present. HIV remains the leading cause of morbidity and mortality. Women and girls continue to be disproportionately affected in Kenya (NASCO, 2007, 2013). Higher HIV prevalence and incidence are reported among women and girls compared to their male counterparts. The traditional social support system remains frayed, and the public health care system is still weak and overburdened. Only 43 per cent of HIV infected persons aged 15–64 years are retained in care.

The narrative of a generalized epidemic changed with the 2009 *Kenya Analysis of HIV Prevention and Modes of Transmission Study*, an epidemiological analysis (NACC, World Bank & UNAIDS, 2009). From this epidemiological analysis, so-called key populations were revealed to have a high, concentrated HIV prevalence. This new scientific data made undeniable the public health importance of recognizing at-risk subpopulations that had previously been ignored by the Kenya government because they were considered socially undesirable and/or involved in criminalized practices. Yet a favourable human rights environment has not been realized and the state is ambivalent at best when it comes to addressing HIV among these key populations, including sex workers, men who have sex with men (MSM), and injecting drug users (IDUs).

Studying HIV support groups in Kenya

This research for this project was conducted in the years 2011–2013 within the parameters of the project, ‘Filling the Gap’: Social Institutions and AIDS in Kenya, Tanzania, and Zambia, which was funded by the Netherlands Organization for Scientific Research (NWO). The aim of the project was to conduct in-depth comparative studies of the social institutions that emerged and accompanied HIV/AIDS in these countries, including transformations in family-based care, the emergence of HIV counselling as a social form, as well as the emergence and transformation of HIV activism and HIV patient-led support groups in these countries. My study focused on the evolution of HIV support groups in providing care and support for PLHIV in Nairobi, Kenya.

A wide consensus suggests that support groups are supposed to promote patients' sense of responsibility toward their own self-care; mitigate the psychological, social and economic impacts of HIV; and enhance HIV treatment and prevention (Heyer et al., 2010; Liamputtong et al., 2009; Mello et al., 2009; Oosterhoff, 2008; T. Nguyen, 2009; Visser et al., 2005; Kalichman et al., 1996). While most research has documented the value of support groups, these studies generally only focus on one group at a particular moment in time. This isolated and static approach make a single story of support groups, and prevents us from understanding the ways that support groups have changed over time in relation to the needs of individuals living with HIV, biomedical advancement, the demands of donors, and global political economies. My research demonstrates the constant interaction of actors in the field of support groups that influence different logics of care and support. While support groups are seen by users as a space of hope (in terms of improving their social, economic, career, and physical situations), biomedical interventions tend to see this space as a system supplementary to medical care provision, with biomedical interventionists defining the content of care and success. Examining a number of support groups over time allows me, first, to avoid a single story of support groups as often presented by researchers, and second to avoid the tendency of disregarding the history of the development of support groups.

In Kenya the influx of funding that accompanied HIV treatment in the early part of the 21st century went hand in hand with a proliferation of support groups. In this ethnography of support groups in Nairobi, I suggest that we imagine such groups as an archipelago: each group is like an island in an urban sea, with members who 'island hop' from group to group³. For this research, I followed nine distinct support groups over a two-year period (2011–2013), using the City Hoppa public transport system in Nairobi, both literally and figuratively hopping between groups. At any one point, numerous support groups may be working together or competing against each other, and members often travel from one part of the city to the other in search of various services or benefits, comparing notes and sharing information through their networks.

³ Similarly, Wenzel Geissler (2013) has suggested the use of the archipelago metaphor to refer to pockets of 'global health' interventions found in Kibera. One is also reminded on James Ferguson's (2005) argument in his article, 'Seeing Like an Oil Company', that globalization only touches down in specific places in Africa to achieve the aims of global actors, skipping over large swathes of the continent. One could argue that the global HIV apparatus not only touches down but also helps to give form to the islands of HIV support found across Africa. This point is taken up further in chapter three.

For the majority of the residents of Kibera, a densely populated informal settlement in Nairobi that served as one of my research sites, life is a daily struggle for survival. While the lives of PLHIV in such settings may not be so different from their neighbours' lives, HIV intensifies poverty (Prince, 2012), and ARVs increases hunger pangs (Kalofonos, 2010). Most adult breadwinners in Kibera rely on petty businesses and casual work, but this becomes a challenge as illness incapacitates people's physical and social wellbeing. In the context of extreme poverty, I found out that PLHIV registered and participated in multiple groups to access care and support services. Support group participants received transport allowances, which people often pocketed and instead walked to meetings. The seemingly small amounts of money attracted high attendance and, subsequently, the multiplication of support groups. Being HIV positive provided economically marginalized PLHIV with an identity that allowed them to demand much-needed material assistance from support groups and other organizations. For many, their active engagement in support groups lasted only as long as the sought-out-for services were offered. In some instances, when personal interests or aspirations were not met, individuals consulted their networks to find alternative groups that would fulfil their aspirations.

My research revealed that with the introduction of antiretroviral treatment, many groups re-organized and re-educated themselves to be able to aid in the provision of biomedical knowledge to the wider community. HIV treatment programs, including PMTCT programs, brought with them an increased need for support groups for those seeking treatment and for the increasingly overburdened health care staff. Support groups were no longer limited to doing community-based HIV awareness trainings or to nursing the very ill in home-based care programs. In response, international organizations tasked with rolling out large-scale treatment programs sought to work with both community-based organizations and institutions.

HIV support groups provided a space where information could be provided to those on treatment that was not being shared in health care workers' consultation rooms because of lack of time. For example, the international NGO, Médecins Sans Frontières (MSF) in 2003 set up the first free HIV treatment centre in Nairobi in Mbagathi Hospital, conveniently located near Kibera, where HIV prevalence was the highest in the city (MSF, 2008). This initiative became the prototype for a hybrid form of intervention. MSF created community-based support groups, required their patients to attend ART literacy training, further trained some patients in group facilitation, and then encouraged them to form their own support

groups in the community where they would share the information they had acquired from MSF with their membership.

Comparing models of support groups in time and space

In this study, I compare case studies of three types of HIV support groups: 1) community-based support groups located in Kibera, 2) health facility-based support groups at Kenyatta National Hospital, and 3) what I call an ‘organic’ support group of male sex workers in Nairobi’s central business district. This comparison allows me to explore how care and support for people infected with HIV is organized, shaped, and experienced in different institutional contexts. Although all three models of support are active today, each emerged at a key point in the history of HIV support and care: community-based groups emerged in the pre-treatment era, health facility-based groups in the treatment era, and the male sex worker group in what I call the post-treatment era, when global funding began to stagnate and to shift toward ‘key populations’. Acknowledging the differences between these three support group models thus also provides a frame that is at once historical and genealogical.

However, as with most models, there are exceptions. Although support groups began to proliferate in health care settings in the age of treatment, at Kenyatta National Hospital (KNH), support groups first formed prior to treatment availability. As a public institution, KNH was heavily burdened with people infected with HIV and provided limited in-house HIV services during this period. The KNH support group model began on a small scale as a ‘post-test club’ to provide ongoing psychosocial and informational support. During HIV treatment scale-up, KNH – working in the context of a stronger national level commitment to respond to HIV and in cooperation with various donors and research institutions – began to both formalize and biomedicalize support groups to enhance prevention and treatment adherence. Patients were renamed ‘clients’ and re-imagined as playing a key role in caring for themselves. Support groups at KNH expanded to accommodate various categories of clients.

In the treatment era, the administration of antiretroviral medication became significant in mobilizing people living with HIV. In Kibera, MSF’s HIV treatment program created conditions that affected the development of social relations. Motivated by the fear that patients in sub-Saharan Africa might not adhere to strict treatment regimens, and the fear of

the negative health consequences that might ensue, access to ARVs was conditioned on participation in support groups (Harries et al., 2001; Popp & Fisher, 2002). The main objective of MSF and other health facility-based support groups was to provide ongoing psychosocial support, and improve treatment adherence and HIV prevention through the sharing of experiences, provision of HIV information, and instilling in patients a sense of responsibility for their own health.

The massive funding accompanying HIV treatment shifted the primary aim of many community-based support groups from providing psychosocial support and advice about treatment adherence to providing material and economic relief. Among low-income populations, especially, support groups were reinforced as sites of economic and material opportunities while the psychosocial benefits that had been the impetus for ART interventions and many groups in the beginning became secondary or non-existent over time. Many Kibera support groups, for example, experienced an influx of material support that included food donations and money (to be used for rent, school fees, and uniforms for children of the infected parents). Very loosely structured, support groups were peer led and facilitated.

In the post-treatment era, as mentioned, international donors began to increasingly focus on so-called key populations. This led to a host of changes in the HIV terrain in Kenya, including the targeting of these key populations and hyper-medicalization of health facility-based support groups. Within the notion of ‘test and treat’, these efforts were inherently treatment- and target-oriented, and they fell short of providing broader psychosocial support to support members, many of whom suffered from multiple and intersecting forms of stigma, as well as being routinely subjected to violence, police harassment, economic hardship, and abandonment by their families – matters that were often considered much worse than HIV infection, and matters that most health facility-based support group leaders were ill-equipped to address.⁴

⁴ There were some important exceptions. For example, Liverpool VCT, a progressive and queer friendly NGO in Nairobi initiated support spaces for HIV-positive MSM as early as 2006. Although they addressed HIV-related topics in the support group, adherence counseling was left to one-on-one sessions, leaving more time in group sessions to focus on ‘living positively’, promoting LGBT rights, and exploring sexual identities. By 2010, when MSM groups were set up at Kenyatta National Hospital for the first time, every effort was made to limit the topics addressed to health issues, rather than advocacy and identity issues.

In response, some of those who had been meeting in a health-facility support group began to form their own support group that met informally in non-institutional settings. The 'Freedom Corner', a male men sex workers who have sex with men support group where I conducted research was one such group, which provided day-to-day social support, crisis-oriented economic and legal support, and a space for members to rework their fragmented and intersecting identities of being homosexual, HIV-positive sex workers. Recognizing the multiplicity of support groups, I draw on the work of Anita Hardon (2006), who highlights how the needs of individuals and/or groups are constantly changing in space and time, as the foundation for analysing the configuration of logics of care and support through support groups. I frame my arguments within the context of global policies, development projects (HIV interventions), and collective and individual care needs and support. Support groups are not as simple as they may first seem. I argue that they are intermediary spaces that provide a context for defining, shaping, and providing care and support for PLHIV. Support groups are a lens through which we can examine and better understand care and support for PLHIV, as well as social and institutional responses to a transforming care and support system.

Widespread HIV treatment has not eliminated the need for care and support. Rather, in varied ways it has brought other lifelong challenges and needs. Via support groups' structures, PLHIV actively negotiate a range of opportunities that arise through funding as well as biomedical technologies in order to call attention to their diverse needs and the challenges of living with HIV. Support groups can constitute a creative space for individuals to imagine, rework, and chart their life course. I examine how these spaces are (re)made, (re)configured, and transformed by different actors in the field. I also explore the shifting needs of PLHIV as well as the shifting terrain of HIV interventions and their implications for care and support.

I argue the shifting needs of HIV may change the meanings of support groups over time. In this vein I explore how practices and activities are (re)imagined and produced. Finally, I try not to lose sight of the contradictions, contestations, and the limitations of support groups' spaces. Even as support groups remain an important component in the care and support of people with HIV, this dissertation shows that these groups can also be potentially stressful and worsen people's adjustment to living with HIV because of unmet expectations and intergroup differences and conflicts. Support groups can therefore also be potentially coercive and alienating. As noted by Siebert and Dorfman (1995), both the sense of belonging and satisfaction of support group members can vary greatly.

Study site

This study was conducted in Nairobi, Kenya. The decision to work in Nairobi was purposive. It was informed by my previous study engagements in the area, and the significant role played by Nairobi in the emergence and evolution of support groups in Kenya. Nairobi is also my home for over three decades which gave me an advantage in manoeuvring the HIV support groups' terrain.

Kenya is located in eastern Africa, bordered by Uganda to the west, Tanzania to the south, South Sudan and Ethiopia to the north, and Somalia and the Indian Ocean to the east. The 2009 census pegged Kenya's population at 38.6 million (Kenya National Bureau of Statistics, 2010) with nearly 30 per cent of the population living in urban areas. The southwest of Kenya has long been considered one of the epicentres of the AIDS epidemic and has consequently been subject to international AIDS interventions for nearly 30 years.

Nairobi, the primary site of this research, is home to a dizzying array of international NGO headquarters and, especially since the early 2000s, has also become both a primary base for and site of global health interventions in Africa.

Figure 1 shows the location of the study site Nairobi in the map of Kenya.



Note: Adapted www.geocurrents.info/gc-maps-by-.../geocurrents-maps-of-kenya

Nairobi

Nairobi is the capital of Kenya, is the smallest of the country's 47 counties with an area of 696km². It is the most populous of the counties, with a population of 3.1 million (Kenya National Bureau of Statistics, 2010). Born out of and shaped by colonial encounters, the city is demarcated along socioeconomic lines that include up-market, middle-income, lower middle-income, and informal settlements. The most densely populated localities are the informal settlements, mainly 80 'slums'⁵ spread all over Nairobi, where approximately two

⁵ The term 'slum' is highly problematic for many reasons and as such I shall refrain from using it when possible. However, it is commonly used in Nairobi to refer to low-income informal settlements, including by the residents of Kibera, where I conducted much of my research. It is also commonly used in global reports, including those published by UN-HABITAT.

million people, or two-thirds of the population reside (UN-HABITAT, 2008; Kenya National Bureau of Statistics, 2010). Though basic amenities are lacking in informal settlements, Nairobi enjoys better infrastructure than both rural areas and other cities in the eastern Africa region, including shopping malls, education facilities, health facilities, airports, information technology, and both national and international economic opportunities – all of which attract migrants seeking both these amenities and opportunities.

The city has a high concentration of health facilities – over 668 public, faith-based, and private for-profit facilities. Of these, more than 378 facilities provide HIV testing, 251 provide prevention of mother-to-child transmission (PMTCT) of HIV services, and 124 provide antiretroviral treatment. Among the public health facilities, Nairobi hosts Kenya’s main referral hospital – Kenyatta National Hospital – and has the highest number of public provincial or ‘level 5 hospitals: Mbagathi, Mama Lucy Kibaki, Pumwani Maternity, and Mutuini Health Centre⁶. Over the years, Nairobi County has consistently reported one of the highest HIV prevalence rates (over 8 per cent) in Kenya (National Council for Population and Development, Central Bureau of Statistics & Macro International Inc., 1998, Central Bureau of Statistics, Ministry of Health & ORC Macro, 2004; Kenya National Bureau of Statistics & ICF Macro, 2010; NASCOP, 2008, 2013).

My exact study locations in Nairobi were support groups located in the sprawling Kibera (also referred to as Kibra) subsection of the city, Kenyatta National Hospital, and a bar based in the River Road area of Nairobi’s central business district.

Kenyatta National Hospital

Kenyatta National Hospital (KNH) is located in Nairobi’s Upper Hill area at the intersection of Ngong Road, Mbagathi Way Road, and Hospital Road. KNH is the oldest Kenya’s national referral, medical research, and teaching hospital (<http://knh.or.ke/>). It became a state corporation in 1987. With over 5000 employees, the hospital has some of the most senior doctors in Kenya but, except for complicated cases, services are mainly offered by registrars, clinical officers, nurses and other specialists. As a referral hospital, it attracts health seekers from all over the country and beyond. Currently, KNH has 23 outpatient clinics and 50 in-patient wards with a bed capacity of 1800. The emergency clinic runs 24 hours, seven days a

⁶ Public health facilities in Kenya are grouped into six levels: level 1 – community, level 2 - dispensaries, level 3- health centres, level 4 - district and sub-district hospitals, level 5 - provincial hospitals, and level 6 - national referral hospital.

week, and handles most emergency cases in Nairobi and its environs. Other outpatient clinics are open from Monday to Friday, 8:00 to 17:00. Most of the services are provided at a cost. Fee waivers are available for those who are unable to afford services. Services that are provided by funded or subsidized projects, including HIV and clinical trials, are free. On average, this hospital serves over 80,000 in-patients and 500,000 out-patients annually. It also has a provision where doctors offer private consultations for their clients at a cost decided by the individual doctors. KNH is the main training facility for medical students from the University of Nairobi (UoN) and Kenya Medical Training College (KMTTC).

For decades, KNH has borne the highest HIV clinical care burden in Kenya. In 1997, 40 per cent of bed occupancy was HIV related, even with a total 190 per cent bed occupancy rate (Arthur et al., 2000). The same study showed that the average number of daily HIV admissions increased from 4.3 per cent in 1988 to 13.1 per cent in 1992. Even before the official acknowledgment of HIV as a national disaster in 1999, KNH played a significant role in providing in-house HIV interventions, mainly diagnostic testing and counselling, PMTCT services, and treatment of opportunistic infections.

After 1999, this hospital was strongly supported by the Kenyan government, other friendly nations and international organizations to undertake HIV interventions. It pioneered a number of vital services such as voluntary counselling and testing (VCT) services, provider-initiated counselling and testing (PITC), prevention of mother-to-child transmission (PMTCT), comprehensive care centre (CCC), as well as a discordant couple clinic, and a model peer-mentor programme.

The CCC, supported by the American-based Centre for Disease Control (CDC) and USAID through Pathfinder International, Partnership for Advanced Care and Treatment (PACT), and KNH Chief executive officer's projects, had over 8,250 patients receiving free HIV/Aids treatment at the time of this study. KNH also introduced post-test clubs and subsequently support groups in 2001. At the time of this study, KNH had 13 support groups: 3 mixed adults, 2 youth, 1 discordant couple, 3 caregivers, 1 health care workers (later split into 2 groups), 1 exclusive men's therapy group, and 2 PMTCT (ante-natal and pre-natal). Most of the people reached here were middle to low income populations.

Kibera

The sprawling informal settlement of Kibera (or Kibra), where the research was conducted, is located 5km southwest of Nairobi's central business district and within walking distance of KNH. It is the largest and most populous informal settlement in Kenya (Kenya National Bureau of Statistics, 2010). It is demarcated into 13 villages: Soweto West, Soweto East, Raila, Mashimoni, Kianda, Olympic, Lindi, Kisumu Ndogo, Kambi Muru, Karanja, Gatwekera, Laini Saba and Makina.

Kibera, like in other informal settlements in Nairobi, is generally characterized by limited infrastructure, high poverty levels, in- and out-migration, and limited public services, such as health facilities, schools, water, sewage, and sanitation. For example, because there is no piped water to houses, it is sold at 5 Kenya shillings (KES; equivalent to 0.05 euro cents) per 20 litres, making water more expensive in Kibera than in more up-market areas. Many Kibera residents live in squalid temporary housing structures consisting of iron sheets and mud-walled houses with earthen floors, rusted iron-sheet roofs, and poor ventilation. Few have cemented floors. Most structures are one-roomed, with each room accommodating between 5 and 10 people. Rooms fetch a monthly rent of between 350 to 800 KES (equivalent to 3.5 to 8 euros). Privacy is grossly compromised.

Kibera is widely known for its lack of basic amenities, particularly toilets. In Kibera people live in 'plots' made up of several one-roomed structures or houses. Some plots, especially those along the river, have toilets that flow directly into the water, though most plots lack toilets. Although there are a few communal toilets, they charge a user fee ranging between 2 to 5 KES (less than 1 euro cent). In most houses, therefore, people use 'flying toilets,' tins or newspapers then are then poured or thrown into trenches or onto pathways or roofs, which have come to exemplify the poor sanitation of Kibera.

Kibera is also on the map as an attraction for film locations. Two international movies, *The Constant Gardener* (Channing, Egan & Meirelles, 2005) and *Kibera Kid* (Collett, 2006), were partly filmed there.

Health services and interventions

Kibera's health care system exemplifies a medical pluralism practice. While the government represented by the Ministry of Health (MOH) is one of the major players in health sector, there is only one public health facility in Kibera's low-income area, the Kibera Health Centre, which is located within the compound of the County Commissioner's office. Four other public health facilities serving Kibera are located in neighbouring middle-income localities

(Lang'ata and Mbagathi hospitals and Woodley and Dagoretti health centres). KNH is three kilometres to the north of Kibera. There are a number of small private clinics, chemists/pharmacies and shops selling over-the-counter drugs, as well as traditional healers and numerous Pentecostal religious centres providing other healing practices in this community. Like in other parts of Nairobi, there are many posters on the walls and electric poles advertising the services of traditional healers, particularly witch doctors from Tanzania and Zanzibar, who promise to solve problems such as lost love, manpower (sexual dysfunction), and infertility.

The high prevalence of HIV, morbidity and mortality rates, and poverty put Kibera on the map for HIV interventions by national and international NGOs and philanthropists, attracting massive funding including material donations. There are six international NGOs and civil society organizations providing HIV services in Kibera: the CDC, MSF, the Africa Medical Relief and Emergency Foundation (AMREF), Sirikwa, Lea Toto, and Carolina for Kibera. MSF has established three clinics in different parts of Kibera, namely Silanga, Kwa Wanga, and Pentecostal Assemblies of God (PAG) church. Local civil society groups provide a range of services: African Medical and Research Foundation (AMREF), Women Fighting against AIDs in Kenya (WOFAK), and the Kibera Community Self-Help Program (KICOSHEP) provide support groups and clinical services; HAKI community-based organizations offer support groups and economic and gender-based violence programmes; TAPWAK provides support groups; and the Centers for Disease Control and Prevention (CDC)-Kenya Medical and Research Institute (KEMRI) runs support groups and a comprehensive care clinic.

Over the years Kibera has come to serve as highly convenient site for intense health interventions and research. In many ways Kibera has become a giant laboratory where health, and in particular HIV-related, research can be conducted. The area is home to many available research subjects who have high HIV rates; it is also close to secure biomedical facilities, and the comforts and conveniences of East Africa's largest and most cosmopolitan city. High poverty levels among Kibera residents results in a bio-value population ready to make itself available for research even when only token transport allowances are offered as recompense.

Livelihood and daily life

The majority of Kibera residents live below the poverty line (Kenya National Bureau of Statistics, 2010). Casual jobs, petty businesses, and philanthropic support are the main

sources of livelihood. Practical needs including food, bus fare, rent, school fees, and clothing are the major concerns for Kibera inhabitants. Notwithstanding, high volumes of financial transactions take place in Kibera daily. This is evident in the presence of a number of money-transfer points (M-Pesa mobile money, Cooperative Bank's Co-op Kwa Jirani, and Equity Bank agents), two banks, a range of convenience stores (kiosks and small shops), green groceries, butcheries, and the roadside vending of all manner of food stuffs and merchandise including second-hand clothes and shoes, toys, bedding, and furniture. There are also multiple music and video shops. According to HAKI, group savings-and-loans facilities handle over 4 million KES circulating in Kibera. There also a number of merry-go-round savings groups and assorted income-generation activities.

Every day before 8:00 in the morning, a multitude of workers who live in Kibera trek to their workplaces in various areas of the city. Still a large number of people remain in Kibera for the day. Of those who remain within Kibera are housewives who tend to household chores, and other women who run petty businesses outside their homes or by the roadside. In their free time women gossip or watch Mexican soap operas and *Afrosinema*⁷ on the television. Men engage in various businesses such as selling second-hand clothing and shoes, running butcheries, making furniture, and selling music CDs or movie DVDs. Jobless men spend their time playing draft and Bao (a mancala game popularly known as '*ajua*') or watching movie video shows that open as early as 10:00, and live English football matches in the evenings in 'video dens'. A good number can be spotted at local spots that serve alcohol in the afternoons. In the evenings, petty traders set up food stalls by roadsides or along the railway line targeting those trekking back from work to Kibera.

Kibera attracts international visitors such as researchers, development workers, and philanthropists, and income received from such organizations is another source of livelihood. A number of organizations link up families in Kibera with philanthropists abroad. Philanthropists may support the whole family or a child in the family with different kinds of support, such as clothes, money for food and school fees, uniforms for children, and/or sanitary towels.

⁷ *Afrosinema* is a Nigerian television series with captivating themes revolving around love, witchcraft, rivalry, and Pentecostalism. It is an important socialization space for women in Kibera. I joined to watch and every time I wanted to leave I was given a preview by those who had previously watched telling me how exciting the coming season was. I ended up watching till the end but it took a long time.

MSM sex workers' site: Nairobi central business district

The male sex workers' support group I studied was based in the city's central business district (CBD). They met nightly in a bar located off of River Road that was sandwiched between two shops. Some resided in various low-income areas of Nairobi County, but because the majority were homeless, many made use of cheap lodging available in the River Road area. A group of 6-8 contributed money to share a room.

The Nairobi CBD is the main centre of Nairobi County, and a hub for local, national, and international businesses and government offices. Most public and long-distance bus transport is located here, resulting in much traffic congestion. Key government offices in the CBD include Parliament, City Hall, Kenyatta Conference Centre (KCC), and the Kenya National Archives. International hotel chains include the Hilton and the Inter-Continental, in addition to many other two- and three-star hotels. The area enjoys many banks, money-transfer points (M-Pesa mobile money), and some of the best restaurants in Nairobi but also has restaurants for all socioeconomic classes. MSM sex workers use nightclubs, bus stops, restaurants, pubs, streets, and parks in this area as their workstations. The study participants also extended their work when necessary to other parts of the city, including the Westlands and Eastleigh areas.

The name 'River Road' has come to stand for the general area of the Nairobi CBD. This area includes not only River Road but its backstreets, where the MSM study support group met; the side streets are very crowded owing to numerous medium and small businesses that sell almost everything that can be imagined of both substandard and good quality. River Road is also the pre-eminent black market of Nairobi, with clothes, shoes, beauty products, generators, mobile phones, computers, televisions, radios, and accessories all for sale. The area also attracts many street hawkers selling accessories and second-hand goods, which makes the area especially crowded and active between 6:00 and 19:00. There are a few banks and many money-transfer points.

Alongside numerous low-end bars, restaurants, and lodges, River Road has more residential flats on top of shops than any other part of the Nairobi CBD. Most downtown sex work is located within this area. Although activity slows down after about 21:00, the River Road area is the only part of the Nairobi's CBD that is active 24 hours a day. Hotels and lodges are 24 hours, catering for long-distance travellers and people, including sex workers with clients, who book rooms on an hourly basis. Lodges charge between KES 100 and KES 500 (about 1 to 5 euros) per night or day. Most hotels charge between KES 500 and KES

3,000 (about 5 to 30 Euros) per night.

The area has numerous private health care clinics, both middle- and low-end. Not far from the usual meeting point of my study participants was a community-based clinic for sex workers, the Sex Work Outreach Program (SWOP). Jointly run by University of Manitoba and Nairobi, SWOP delivered basic HIV and sexually transmitted infection (STI) prevention, care, and treatment for both female and male sex workers. At the time of my study, their services included information on safer sex practices, condom education and distribution, HIV testing and counselling, STI screening and treatment, risk reduction counselling, antiretroviral medications and HIV basic care, tuberculosis screening and referral, post-exposure prophylaxis services, emergency contraceptives provision, and psychosocial support and referral. Approximately a kilometre away from the meeting point was the Nairobi City County's Casino Clinic, a treatment centre specializing in HIV testing, care, and treatment; STI testing and management; and tuberculosis testing and management, among other services. Some of the male sex workers' accessed HIV, tuberculosis and physical assault emergency services from Casino clinic. Near the support group meeting space there were also several small private conventional clinics and many advertisements for traditional healers. Some of the support group members accessed health services in other parts of Nairobi, mainly Liverpool VCT Health and KNH.

Outline of the thesis

The thesis is divided into eight chapters. Chapter One is an introduction that provides a glimpse into the terrain of support groups in Nairobi, describes the methodology and ethical considerations and negotiating social licence, and offers my reflections on studying sensitive issues. In Chapter Two, I provide a basic background to the study, examine the origin of support group paying much attention to HIV, define key concepts including support, care, support groups, and offer a critical overview of theoretical framework of bisociality in shaping social relations around HIV. In Chapter Three, I trace the historical development of HIV support groups in Kenya, as marked by three important historical moments in the HIV landscape. Recognizing the multiplicity of support groups, I explore challenges and opportunities, the dynamics, diversity and specificities of the support group landscape, which is stimulated by both internal and external forces over time. In Chapter Four I explore HIV

support groups in the treatment era and beyond. I focus on three time periods: a national disaster (1999–2002), which was a time of desperation with devastating effects of increased HIV/AIDS; ‘resurrection time’ (2003–2009), when HIV treatment arrived accompanied by massive funding, resulting in saving lives; and; 2009 and beyond, the post-treatment era. Chapter Five, which was published in 2014 in *Anthropology and Medicine* and co-authored with Eileen Moyer, examines how social support changed in times of HIV, focusing on transformations in family- and community-based support in a context of rapid urbanization and shifting global HIV-prevention and -treatment priorities. Chapter Six provides an in-depth description of the emergent functions of support groups as PLHIV live longer, and specifically how support groups respond to male sexual issues. I present a case study of a men’s sex therapy group that met at KNH, which examines the changing needs of clients on HIV treatment and the potential of a health facility-based support group’s responds. This chapter, which was also co-authored with Eileen Moyer and published in *Culture, Health and Society* in 2012, depicts how the sexual and reproduction needs of a group of particular men are explored in an institutional setting. Chapter Seven offers a case study of male sex workers, in which I describe an informal and organic support group of MSM, explore their complex needs and challenges, and how the support group responds to the needs of its members. Lastly, the conclusion considers the implications of support groups in the care and support of PLHIV.

CHAPTER 1

METHODOLOGICAL ISSUES

Apprehending the fragmented object of HIV support groups in Nairobi

From the outset of my research I expected to work with multiple support groups. Often, ethnographers focus on a single village or neighbourhood. In my case, it was clear that an in-depth study of one support group would not suffice given my objective to understand how support groups have emerged and transformed over time. Because I had already been working in HIV-related research projects for more than a decade before I began my PhD, I expected the object of my research, HIV support groups, to be fragmented and constantly in flux. With this in mind, I developed a methodology to allow for this unpredictability.

Oftentimes, what goes into the production of knowledge, including steps, methods, conditions, and various factors, is underanalyzed due to lack of reflexivity (Latour & Woolgar, 1979). In this chapter, I begin by providing a bit more background about the context of my study in an attempt to highlight that my research took place in the context of continuous change, particularly in regards to global, national, and local responses to HIV. I also argue that my flexible methodology allowed me insight into the ways this shifting context shaped support groups, as well as allowing me ethical access to hard-to-reach communities and research topics. Finally, I reflect on my personal experience of working with different communities and on 'sensitive' issues, on the challenges of conducting ethnography on a topic that has attracted massive funding, and on being a female researcher studying a male sex therapy group and MSM sex workers in a context where both homosexuality and sex work are criminalized and highly stigmatized.

The changing tides of HIV research

HIV support groups occupy a centre stage in HIV interventions, touching on the day-to-day lives of people living with HIV and their loved ones, and also contributing to social transformations related to expectations of care and support at the family, community, health facility, national, and even global levels. Conducting research on the evolution of HIV support groups in Nairobi at the time I did proved significant in several ways. HIV support

groups were first conceived and formed in Nairobi before being exported to other parts of Kenya. Nairobi also continues to be the testing ground for new models of support and is also home to most of the national-level PLHIV advocacy and support organizations, which generally represent Kenyan PLHIV in national and international contexts. Because I was interested in studying how support groups were changing within the context of shifting national and international debates, Nairobi was the most logical place for my research.

During my research, the narrative of HIV being a ‘death sentence’ was slowly changing in Kenya; an international discourse hailing the possibility of ‘zero new infections’ and ‘an AIDS-free generation’ was beginning to take hold. The country had rapidly moving from political denial to political commitment, from a lack of access to treatment by those who desperately needed it to widespread access to treatment, and from limited funding to massive funding. Amorphous interventions gave way to evidence-based interventions; and the rapid proliferation of support groups was calmed, as the hype of support groups faded and the groups were reinvented.

These changes were a response to pressures in Kenya for sure, but also to power shifts taking place on a global scale, including two key events in 2008: the international debt crisis and the election of Barack Obama in the United States. After 2008, US policies for funding HIV prevention and treatment initiatives began to focus on evidence-based models, practices, and interventions that called for greater efficiency and accountability. The rest of the world quickly followed suit. Language from the world of international development was increasingly beginning to drive HIV interventions, such as ‘value for money’, ‘result-based’, ‘strategic investment’, and ‘epidemic-driven strategy’. With US Secretary of State Hillary Clinton leading the battle cry, international donors re-invigorated rights-based advocacy discourses reinforced by epidemiological discourses, led to the emergence of new categories of people and groups in Kenya: ‘key populations’, including MSM, or men who have sex with men, were created when global development intersected with Kenyan epidemiological studies. Of supreme significance were the contested moral discourses around homosexuality that were common and heated in the public domain in Kenya, including during the 2010 constitutional referendum and the hiring of a new Kenyan chief justice, whose sexual orientation was publicly questioned.

At a time of my research, and partly in response to shifts in global funding and national public health strategies, numerous community-based support groups were actively changing from a model in which they were nearly completely dependent on donors to one of

economic empowerment, mainly through a range of income-generating activities and table banking⁸. Some were more successful than others. Some groups also retrained and repositioned themselves to take up emergent social concerns such as reproductive health and sexual issues. Three support groups, which had begun with an inward focus, providing immediate support to members, had grown into national-level NGOs, broadening their scope to include the provision of health services at their headquarters, with functional laboratories, a clinical officer, a lab technician, and nurses. They also continued to provide limited home-based care services for neglected patients.

Another development that took place during the time of study was the discovery of *kikombe cha babu* in Loliondo, Tanzania. *Kikombe cha babu*, or ‘grandfather’s cup’, is a herbal concoction produced by a self-proclaimed Tanzanian prophet called Mr. Ambilikile Mwasapile. People from all over eastern Africa and beyond flocked to Loliondo to stand in long queues for the chance to drink the wonder drug that he claimed would cure a number of diseases, including HIV. It was speculated and rumoured that many people who had travelled to Loliondo were abandoning ARV treatment. The existence of *kikombe cha babu* generated discussions in most support groups and also renewed discussions of treatment adherence, particularly in KNH health facility-based groups where traditional medicines were typically dismissed as simultaneously unscientific and a threat to ARV efficacy.

Reflecting on class and the need for contrasting case studies

One of the challenges of conducting anthropological research at home is that it is sometimes difficult to recognize the ‘strangeness’ of one’s own society. For me, my eyes were opened with my encounter with the Netherlands Cancer Institute, the Antoni van Leeuwenhoek

⁸ Table banking refers to small-scale financial transactions carried out in an informal group setting. In Kibera there were two types of table banking: merry-go-round and group savings and loan (GSL). In the merry-go-round model, each group member contributes an agreed amount of money and the whole amount is rotationally given to one member. GSL allows members to contribute a certain agreed amount of money or more weekly, biweekly, or monthly. The money is saved in the groups’ bank account and given back to members as savings at the end of the year. The GSL offers simple loans to members, who repay the loan before the end of the year at very low interest. This allows those who cannot access credit from financial institutions to start up income-generation activities. Care International introduced GSL to Kibera HIV support groups and provided members training. By August 2012, 50 GSL groups were registered under the HAKI community-based organization.

Hospital in Amsterdam. My visit to this state-of-the-art facility with a colleague triggered in me an immediate reflection on health care in Kenya. I was amazed at the fact that the Dutch hospital was a public health facility. Back home in Kenya it would be in the class of private, for-profit high-end health facilities. This made me wonder aloud about the health care system in Kenya and also to begin to reflect on how the middle class in Nairobi almost always first seeks services from these high-end, private facilities, but often ends up in the dreaded public health facilities when they run out of money. Discussing this with my supervisor, I realized that little research had been done on the way that class shapes access to HIV care and support in Africa, despite all the rhetoric in international economic discourses about the growing middle class, as well as increasing inequality in African cities. With this in mind, I began to conceive of conducting contrasting case studies to try to capture some of the differences across support groups.

During preliminary fieldwork, I interviewed key informants who worked in middle- and upper-class health facilities to learn about support groups that I might eventually study. A senior professor of oncology who worked for a state-of-the art, private, for-profit hospital in Nairobi remarked:

People who participate in support groups are after some benefits. They have nothing to lose – they can shout in the streets. But the rich people we deal with cannot join support groups.

They pay heavily for privacy. They order the latest drugs from abroad.

The ‘benefits’ to which the professor referred were material benefits. His statement triggered a number of questions: Were support groups only for material benefit, and therefore meant for the poor? Are there other, non-material benefits to participating in support groups? If the material consideration is removed, what else might motivate people to attend support groups?

Soon after, I spoke to the KNH’s HIV voluntary counselling and testing (VCT) manager, Dr David Bukusi. He informed me about support groups for middle-income PLHIV that were run by Family Health International’s (FHI 360) Gold Star Network Project⁹ and referred me there. The FHI project manager informed me that because support groups were

⁹ The Gold Star Network project aimed at increasing access and ensuring continuity of treatment among those middle-income patients who sought services from private, for-profit health providers but couldn’t continue paying for ARVs from these establishments. Gold Star project, therefore, organized with the public sector for free ARVs to be dispensed through the private health providers to patients or clients who were not comfortable seeking services from public health facilities. Gold Star also offered hotline counselling services to their clients.

synonymous with material donations to the poor, a label with which middle-income patients did not want to be associated, the project called such support groups ‘care’ or ‘professional’ groups, or even ‘dating’ agencies. These preliminary conversations made it clear that my idea for a contrasting study design was feasible, but also that I would have to be flexible and open to the possibility of support group structures that challenged the status quo. My main interest at the preliminary stage of my research was to capture class differences, but in time I also began to see the importance of gender and sexuality.

Mapping the (un)mapable: ethnography as a methodological approach

As my research was embedded in a larger ethnographic study, there was no question that I would take an ethnographic approach. This choice also fits with my previous experience and training in medical anthropology. I had been engaged in qualitative HIV research for almost a decade by the time I began my PhD, and much of that was embedded in larger anthropological studies, which emphasized the importance of participant observation and conducting research beyond the clinic. I knew that such an approach made it easier to talk to people about sensitive issues, including HIV, sexuality, and financial matters. Ethnography would allow me to conduct the research I had in mind because I would need to access to diverse and less visible groups to pull it off, including the privacy-loving middle class.

In February 2011, I began 20 months of intensive fieldwork. I began by conducting interviews with key informants and mapping support groups, with the aim of gaining an understanding support group typologies to guide me in sampling groups (for the knowledge mapping approach, see UK Home Office, 2006, p. 14). Because I was interested in studying the differences between community-based and health-facility-based support groups, through key informant interviews and structured observations, I began by mapping the support groups at the hospital and then moved on to Kibera.

KNH support groups

Working with peer mentors, I identified 14 support groups: three of mixed adults (men and women), two of which met on Saturdays and one on Thursdays; two PMTCT (antenatal and postnatal) groups; one group each for youth, teenagers, and adolescents (the division of these groups deserves a study in itself); a group for alcohol and substance abuse; and one for

discordant couples. Three groups also existed for caregivers of adults and children with HIV. Finally, there was a health care workers' group, which met every Wednesday afternoon. These groups allowed the continual enrolment of new members and were all active at the time of my study. The groups were co-facilitated by trained peer educators or mentors who were HIV-positive 'expert clients' and nurse counsellors.

The diversity and uniqueness of the groups troubled my sampling. As it was clear I would not be able to select a representative sample from such diverse groups, I decided to select groups that seemed unique to KNH, keeping in mind my goal of researching the differences among groups. Before making my final selection, I attended two of each of the group's sessions. Each group could have made important contributions to my study, but I could not include them all. Apart from their diversity, meeting times also informed my sampling in the end. Spoiled for choice, I decided I needed to be pragmatic. I did find that groups in the same category were similar and members were allowed to attend any of the groups in their category. For example, the three adult mixed groups offered similar content.

Out of the 14 groups, I selected five: a mixed adult group, a youth group, the alcohol and substance abuse group, discordant couples group, and a healthcare workers' group. In the course of the study, some groups at KNH were disbanded while others were formed. For example, an adult group that met on Thursdays, which was, mainly attended by Seventh Day Adventist church followers and those who worked on Saturdays was dropped because of decreased funding for support groups. However, a month later two new groups were formed: a men's sex therapy group and another youth group that met on Fridays. The alcohol and substance abuse group was also dropped due to poor attendance; active members were absorbed into the mixed adult groups. When the men's sex therapy group began, I added it to my study, in part to study the formation of a support group, but also because I expected it would provide a unique opportunity to study a topic about which very little had been written.

Because money was not offered to support group members at KNH, there was almost no in-fighting about economic issues. The only exception was the healthcare workers' group, which ended up splitting into two groups following the offering of funding from Mildmay, a transnational NGO. The splintering occurred along class and professional status lines, with the better trained nurses claiming the Mildmay spoils for themselves, while the service workers were left to regroup.

Support groups in Kibera

In Kibera, most key informants (the district officer, PLHIV activists, local and national NGO staff) referred me to the Kibera Post-Test club (KIPOTEC) and the Nairobi Post-Test Club (NEPOTEC) as my starting point in mapping support groups in this area. In an eight-by-three metre maroon shipping container donated by AMREF that served as the KIPOTEC office, I met with a soft-spoken man known as ‘Chairman’ to discuss my research. He kindly gave his regrets, informing me that I was ‘too late’ to study support groups. He told me that many support groups were currently dormant; some had closed because of internal wrangles; others had split up. His primary concern seemed to be the failure of these groups to pay KIPOTEC the yearly subscription fee that was used for administration purposes. Nonetheless, Chairman printed out for me a list of the 41 support groups in Kibera that were registered with his organization. This conversation with Chairman and similar discussions with other key informants unsettled me, as I realized how insufficiently I was informed about the dynamic ways that support groups changed and worried whether I would ever understand the complexity, let alone capture or map it.

With Chairman’s list in hand and his promise to help me track down the physical addresses of these groups, I set off to find Kibera’s support groups. As mentioned, Kibera is an informal settlement, so the physical addresses people had provided in their registration details could not be found on any existing maps. When we failed to locate a group’s physical address, Chairman summoned the group’s leaders to the KIPOTEC office. During my meetings with group leaders I would introduce my study and hold general discussions about group membership, leadership, gender issues, participation, activities, and challenges. The goal was to get a broad picture of the similarities and differences among support groups in Kibera.

From the original list of 41, we were only able to trace eight active groups. Eighteen were dormant or inactive, a further eight had encountered irreconcilable differences and had split up, and seven were non-existent. The difference between dormant and non-existent groups is important: dormant groups still had a leader and a membership list. These groups could reconvene and come back to life in the case of need or in the event that donor funding became available again. I only considered a group non-existent when their leadership could not be traced. The leaders of the dormant groups and those that had split up reported to the KIPOTEC offices promptly upon receiving a call from Chairman. I was informed that since there was no funding, most group members had diverted their attention to daily survival activities but could be mobilized on short notice for various activities. Of the 18 dormant

groups, 10 had transformed into GSLs and had become affiliated to HAKI.

No doubt, it was hoped that my presence signalled the return of funding. Most of the groups that had split up had done so following arguments about leadership, transparency, the ownership of groups, the distribution of opportunities, or the management of funds. Some observed that such wrangles often began with election of leaders. Those who were not satisfied with election results often split to form new groups. Those who made first contact with donors usually claimed ownership of the groups and would sideline other group members, taking custody of a group's registration certificates and monetary contributions and dismissing calls for new elections.

Many of the leaders of these splinter groups accused the original group leaders of embezzling donor funding, which the groups generally referred to as "our money" rather than project money. A 60-year-old member of a group that splintered off from the Catholic Organization of Women with AIDS in Kibera (COWAK) lamented how their leader claimed a group-owned school as her own property. A member of a second COWAK splinter group told me the same story. This case, like many other support group claims about corrupt leaderships, had been reported to the area chief for conflict resolution. In many instances the area chief failed to solve the conflict and would forward the case to the district officer.

Original group leaders whom I interviewed faulted splinter groups for not understanding the dynamics of donor funding for projects. The KIPOTEC secretary said:

Some people do not understand about donor money. They think project money is personal money – that when it comes it has to be divided among members. Like now we have an activity for children tomorrow, the foodstuff we have received is for those children. As you saw, as soon as the vehicle [delivering the food] left, these women arrived to demand *msaada*. Because they are living with HIV they think any support we get should be for them. One time a woman refused to leave this office, demanding that she be given *msaada* that had been brought for people living with HIV. We had to use force to get her out of here.

I found out that some groups did not subscribe to KIPOTEC, as they could not raise the yearly subscription fee. Other than KIPOTEC, there were other networks support groups could subscribe to such as The Association of People with AIDS in Kenya (TAPWAK), HAKI, Network for People with AIDS in Kenya (NEPHAK), and Women Fighting against AIDS in Kenya (WOFAK). A few groups in Kibera had subscribed to multiple bodies.

I also found that support groups could serve various functions such as economic empowerment (mainly table banking and bead making) and acting as early childhood centres.

Employment opportunities included tracing people who had halted their tuberculosis treatments, and distributing donations including foodstuffs, uniforms, soaps, and sanitary towels. Because of the varied functions of these groups, people often joined two or more multiple support groups even though there had been a significant reduction of aid across the board. There were also a number of PLHIV who belonged to Kibera support groups and groups organized by KNH, or to the Dreamland support group located in the Lang'ata area. Each group provided some kind of benefit to members. The Dreamland project supplied porridge flour, Kibera groups provided employment opportunities, and KNH groups provided HIV information and psychosocial support.

Margaret Jaika, who was a member of a Kibera and a KNH support group, told me she attended the KNH support groups to refresh her HIV knowledge and for psychosocial support because sometimes she feels very low and has no one to share her feelings with. Going to KNH provided her with the opportunity to discuss issues affecting her, ask questions, and get advice from other group members. She did not get this kind of support from her Kibera support group, which only focused on economic support through merry-go-round activities. It is therefore simplistic to conclude that PLHIV in Kibera only join groups for material purposes. According to Margaret, HIV could not be solved with merry-go-round funds alone. She also had concerns about side effects, how to negotiate condom use, and how to care for her HIV-positive child.

New support groups also continued to emerge in Kibera at the time of the study. These groups were formed by individuals who had been recently begun ART treatment and who had attended treatment literacy trainings. As part of my research, I also attended two treatment literacy trainings in Kibera, organized by MSF and HAKI. At the end of the three-day treatment literacy training, those who completed the training were given the choice of joining existing support groups or forming new ones. In both of trainings I attended, participants formed new groups. They faulted existing groups for turning into economic ventures marred with infighting. They also reasoned that during the three-day meeting they had become familiar with one another and therefore it would be easier for them to interact.

From the eight active groups affiliated to KIPOTEC and four others that subscribed to other networks, I selected three Kibera-based community support groups for in-depth study. These were a women's support group organized by HAKI, Kwa DO, and the Tumaini Support Group. The selection was informed by meeting days, gender participation, activities,

and affiliation. Since the KNH-based support groups I had selected met on Saturdays and Wednesdays, in Kibera I selected groups that met on Mondays, Tuesdays, and Thursdays.

Freedom Corner: an organic support group of MSM sex workers

During the mapping exercise in Kibera I met Moses¹⁰, a support group leader who informed me that he was bisexual before asking if I knew about a group of ‘*kuchus*’ from Kibera who, for fear of being killed or ostracized due to their sexual orientation, met in Nairobi’s downtown. Including this group would provide insights into HIV socialites of marginalized communities. The term ‘*kuchu*’ is borrowed from Uganda, where it is used to refer to homosexual men, and is commonly used as slang among homosexuals in Kenya. In the course of our conversation, I learned that the Kibera *kuchus* who were meeting in downtown Nairobi were homosexual male sex workers who were also HIV positive. When I said that I would be interested in meeting with the group downtown, Moses hesitated, citing confidentiality issues.

Three months later, while attending the 2011 Biennial HIV and AIDS Conference in Kenya, I chanced upon John Mathenge, the director of Health Options for Young Men and AIDS (HOYMAS), at the National AIDS and STIs Coordinating Programme (NASCO) stand. After introducing my study to those gathered there, John asked if I could also include his group, a support group for MSM sex workers, which turned out to be the same group Moses had mentioned earlier. Even with his support, however, it took several months to gain access to the group. First, he interviewed me extensively. Next I was invited to a workshop for the dissemination of findings from a participatory study that was conducted by male and female sex workers on the experience of commercial sex workers in four African countries. The research, funded by UNDP, had been conducted by Kenyan and South African sex workers under the guidance of Mr. Boyce, who had earned his master’s degree in medical anthropology at the University of Amsterdam. During the workshop, in the presence of about 20 stakeholders, including MSM and MSM sex workers, I was surprised when John introduced me as a “friend and supporter.”

Three months after my first meeting with John, he again invited me, this time to a

¹⁰ When quoting public figures, including support group leaders who gave permission, I use real names. In the case of people who shared confidential information with me, I use pseudonyms. Given the risk of publicly proclaiming non-heterosexual identities, I generally use pseudonyms when quoting or referring to people when it would mean putting them at risk. Moses is a pseudonym.

training workshop for MSM sex workers sponsored by APHIA*Plus* and facilitated by a group called Support for Addiction Prevention and Treatment in Africa (SAPTA). It was in this meeting that I finally met the 24 MSM sex workers who were members of the support group. John introduced me as “his friend studying at the University of Amsterdam.” The mention of Amsterdam, I would soon learn, would work miracles in building trust and rapport with the group. To them, being to Amsterdam implied I have sufficiently mingled with MSM, and therefore non-judgmental, and a supporter of the group. I was applauded, with smiles, and acknowledged as one of them. After the second day of training, those in the training invited me to their usual meeting place, known as ‘Freedom Corner’.

The ongoing elusiveness of the upper and the middle class

From the onset of this study I was determined to contrast the experiences of PLHIV in different demographics in Nairobi. Contrary to De Waal’s (2005) assertion that it is easy for most people to mobilize around HIV, I found it proved a challenge for many, including those like the MSM who had to conceal their identities from neighbours and family, as well as for the upper and middle classes in the general population. Perhaps as the oncology professor quoted above noted, those who were from the lower class had less to lose than those from the middle and the upper classes, as they were more concerned with privacy. In Kenya, HIV-related stigma is generally higher within the middle- and upper-class communities.

My attempt to map middle- and upper-class support groups began with Family Health International’s Gold Star project. The Family Health International Gold Star Network project funded by PEPFAR through Pathfinder International’s AIDS Integrated Population and Health (APHIA) Plus project facilitated support groups for middle-income populations. The project targeted those who sought services from private doctors or health facilities but who could not pay for the ARVs from these private health facility establishments, leading to non-adherence to HIV treatment. In addition, Gold Star Network had noted treatment mismanagement of middle-class PLHIV who sought services from private practitioners:

We found the private practitioners took advantage of the ignorance of their clients. Patients were prescribed for the latest HIV treatment. Instead of starting with the first line ARVs, some of them were put on second line or the doctor without any justifiable reasons could change prescriptions, therefore most patients quickly moved from first line to second line (Gold Star Network staff).

The Gold Star project stepped in to organize medicines from public health facilities to be dispensed by private establishments for such patients. The Gold Star manager revealed that six support groups – dubbed ‘care’ groups – were formed through this initiative.

Based on my preliminary research, I had planned to include some Gold Star groups but by the time I returned to Kenya to undertake extended research, those groups had wound up or become dormant due to a lack of funding. This remained the case throughout the entire period of my study. Apparently the same group members who claimed they did not want to be associated with material aid now wanted their meetings to be funded. It was not that they did not want to benefit from donor funding, they just did not want it to be referred to as ‘support’. Despite efforts by the project staff to encourage groups to continue meeting, the groups disintegrated save for the Urbanites support group, which existed before becoming incorporated into the Gold Star project. On the funding of middle-upper class groups, a PEFAR representative noted:

The American middle class cannot fund the middle class in Kenya. Those middle class people have money and can afford to pay for counsellors. They can also go to where these groups are found if they need to meet with other people living with HIV.

The Gold Star project manager referred me to the Urbanites group, the only group that remained active. I contacted the group’s founder and leader who agreed to an interview, and she was positive about the group participating in my study but worried about confidentiality issues. I spent three months negotiating access to the group before they finally agreed to allow me to attend.

People who are diagnosed with HIV in these communities often deny their infection and refuse treatment, even when it means death. They often report depression, and go to great lengths to conceal their HIV status. The following is an extended quote from a leader of the Urbanite Support Group, which caters to young, middle-class, educated people:

When I tested HIV positive I went to KENWA [Kenya Network of Women with AIDS]. At KENWA, if you are HIV positive, you must attend support groups. That I did for a while. But I did not fit in the group, I felt out of place and uncomfortable being in the group because of education and class differences. The people in the group were very desperate and poor. ... I had just graduated from the University of Nairobi. I felt I had lost everything, work and friends. I just felt the need to organize young people like me – the likeminded. I met two girls

who had come to KENWA for formula milk¹¹, and we hooked up. In 2007, I had my story in the papers and working people¹² called me for private discussions and many others emailed me. I then started a blog to share ideas because I realized there were many questions and concerns out there.

In January 2008, I managed to have a group meet face to face for the first time. That is how I started a support group for young working HIV-positive people. I was both happy and sad with the group. Happy because when some people cried in their first and second meetings, and after hearing from others and getting information on HIV/AIDS, the next time you meet them on the streets they are happy. ... They just needed information and emotional support to move on. ... Sad, because some did not accept being HIV positive. One young lady whose mother was a nurse refused to disclose to her mother, she also refused to take ARVS and told me, 'This disease is not for me. ... I am educated and from a rich family'. Because she was educated and middle class she did not belong to the class of PLHIV: the uneducated and poor. She refused to take ARVs and she died.

Another one, a lawyer who had just wed and had a three-month-old baby also refused to take ARVs. ... And many others died. It was too much for me. Then I felt I needed to reach out to more educated young people. I went on television telling about my story. Some of my group members called and told me they did not want to be associated with me in public. This has affected support group meetings. Some even dropped out of my social media platforms. I used to write for some magazines, and some refused to read my articles saying they did not want to be associated with them. One young lady sent an email to me saying I should never write to her again because she did not want to explain to people who I was.

In the end, however, the group sessions were erratically organized and marked by continuous last-minute postponements. The one group session that took place during my study was poorly attended with only the leader and one group member present.

Unlike in the works of Farmer (1996), where HIV was entrenched among the poor or otherwise disempowered, I found HIV seemed to be entrenched among the middle income or otherwise empowered. The director of the Kenya AIDS NGOs Consortium (KANCO) painfully told me how an upper-class friend of his had accosted him about the loss of his son

¹¹ Formula milk is one of the infant feeding choices for HIV-positive mothers.

¹² Working people' here means people with jobs, the educated middle class.

to 'these things of yours', unable to bring himself to mention HIV/AIDS. The director wondered why his friend only came to him after his son had died, and not before to save him. When HIV or AIDS appears among the middle and upper classes, it is silenced (Kamau, 2009). The young middle-class PLHIV preferred to keep their HIV status secret, and very few participated in KNH support groups; they were a kind of hidden community. Of those who participated in KNH groups, some ended up forming their own group within the larger group. In their smaller group they met outside KNH to socialize, which excluded those with lower incomes. As committed as I was to conducting a contrastive study between support groups serving lower, middle, and upper class people in my study, finding suitable groups proved both problematic and informative.

Another key informant told me about a support group at MP Shah Hospital, which is a private hospital with a middle- and upper-class clientele. At MP Shah Hospital the receptionist referred me to the hospital's HIV counsellor who told me about a secretive support group organized by the health provider:

It is a very secretive group. ... I came to know about it because one of the group members who thought I was HIV positive approached me to join the group. So I know the group exists but it is very secretive. In fact, if you pass by the notice board and you will see an anonymous memo from that group. People who come to this hospital are rich and very secretive. Even when they test positive they go to private doctors who see them. We do not have access to them. It is not easy to get patients who come here to attend a support group. ... I heard about one that was organized by a private doctor who saw HIV patients privately. ... Apart from counselling them when giving the HIV results, we never see them again; they see the doctors privately.

A year into my study, I met Joyce, who had been recently hired for a project run by KNH's VCT centre. Joyce told me about a group for men and women of both lower and middle incomes where she was the group's secretary. After prolonged negotiations the group agreed to be part of my study, however, in the end my access to this group also suffered from continued postponement of group sessions.¹³ Although at KNH I was able to observe some of the class dynamics of support groups, especially in the health care workers group, in the end my insights remained limited and the support groups catering to the middle and upper

¹³ Negotiations involved communicating through Joyce. The group members were concerned about confidentiality, and would only allow a medical doctor to their group for informational benefits. Along these lines, we agreed that I could give a talk on PMTCT even though I was not a medical doctor.

classes remained elusive.

While I was convinced there were significant insights to draw from the inclusion of different socioeconomic classes, my efforts to include a middle-class MSM group to contrast with the MSM sex workers group did not bear fruit either. One program manager noted that because of homophobia, middle-class MSM remained invisible, accenting the dilemmas of coming out of the closet and the desire of many to remain silent.

Data sources and collection

The data for this dissertation come from observations of HIV support group meetings, interviews and informal discussions or conversations with group members, life histories, key informants, community members and media reports. Whereas the use of multiple methods often allows for the generation of a coherent picture of the object of study, in this case drawing on different sources of information and relying on different data collection techniques resulted in the destabilization of a coherent story about support groups. The research participants included people with HIV who participated in HIV-related groups, including not only those that identified as support groups but also those who refused the name, preferring to call themselves 'care groups' or 'professional groups'. Key informants included PLHIV activists, support group leaders, key personnel working in HIV service-related NGOs and community-based organizations, as well as spokespeople for numerous government agencies involved in the making of HIV policy, both in Kenya and internationally.

I had planned to conduct research in two phases, starting with key informant interviews and a mapping exercise to inform the second phase of the study, however, in practice the two phases overlapped. A good number of the high-level key informants I had wanted to interview in the first phase of the research, including the directors of national NGOs who had played a key role in the emergence of support groups in Kenya, were often on business trips abroad. I caught up with some of these directors at the 2011 Biennial HIV Conference in Kenya and the 2011 International Conference on AIDS and STIs in Africa (ICASA) in Addis Ababa, both of which I approached as research sites as well. Due to the prolonged absence of the directors, other long-serving staff were selected for some key informant interviews. Furthermore, a strict adherence to this phase would have denied me

opportunities to seek clarifications and more information from key informants. Allowing for some flexibility in this respect allowed back and forth discussions with study participants and a more iterative learning process.

This dissertation draws on many types of data collection, described below, including 38 key informant interviews, 32 walking sessions, 58 in-depth interviews, 8 focus group discussions, 16 case histories, 488 participant observations (192 with MSM sex workers, 40 with the Kwa DO support group, 46 with the HAKI support group, 45 with the Tumaini support group, 16 with the KNH youth group, 16 with the KNH adult group, 16 with the KNH adult mixed group, 16 with the KNH discordant couples group, 10 with the KNH PMTCT group, and 50 with the KNH health care workers' group), and media reports.

Key informant interviews

I started research with key informant interviews to gain overall insights into the topic, and to build research relationships through which I could share feedback and seek clarifications on the phenomenon of support groups. From previous research experiences and media documentation, I drew up a list of stakeholders that included representatives of government agencies (NACC and NASCOP), donors, civil society (NGOs, faith-based organizations, and community-based organizations), people living with HIV, and public figures who had played a key role in HIV programs in Kenya. My list of key informants increased through snowball sampling. I sent emails to organizations and individuals requesting interviews. The email introduced the study and included the aim and objectives, procedures, and description of participation. I attached copies of the research permit, ethical approval and consent forms. Most organizations and individuals responded positively and set up an appointment for interviews. When I did not receive any response, I followed up with telephone call.

I let the organizations select a suitable person for the interviews. Some of the directors of international HIV implementing organizations asked me to provide feedback on whether the selected staff performed their duties effectively. While in most organizations and government agencies I held discussions with one staff in a one-on-one interview, donor organizations usually presented two or three interviewees in one sitting.

Besides my initial list of key informant interviewees and referrals from those, different forums, such as the Inter-Agency Coordinating Committee meeting, workshops, and conferences helped me identify key informants. For instance, after an interview with the then

NACC Director, Professor Alloys Orago, I got an invite to and upcoming Inter-Agency Coordinating Committee meeting. There I met with prospective key informants who were representatives of various HIV stakeholders including government agencies, donors, civil society organizations, national NGO directors, and people with HIV.

The KNH HIV peer mentors' office and the KIPOTEC offices in Kibera emerged as sites for key informant interviews. The HIV peer mentors' office is located on the ground floor of the Comprehensive Care Centre within the KNH complex. The two-by-two metre room held three chairs, a desk, and a laptop and was used by seven peer mentors. This was their reporting station before they dispersed to various clinics and wards to provide supportive counselling to people with HIV/AIDS within KNH. It was also where they congregated for breaks and left their personal items when they were out in the clinics. In the KIPOTEC shipping container-office were at least 10 chairs, a large office desk, two computers, and a printer. People living with HIV in Kibera frequented the office, particularly support group leaders.

Using these offices as my own workstations helped keep me in regular contact with peer mentors in KNH and support group leaders in Kibera. In these offices I learnt a lot from their discussions. I also held numerous discussions and found the people I interacted with more knowledgeable about support groups than those on my original key informant interview list. At KIPOTEC I engaged in reflections with support group leaders on the emergence, evolution, dynamics, and politics of support groups; people in the KNH peer mentors' office provided me information on different aspects of support groups, social support, and participation in support groups. These discussions and key informant interviews allowed me to gain insights into HIV support groups and to reconstruct the history of support groups in Kenya.

Apart from being source of information, maintaining good relations with key informants in Kibera and KNH was a worthwhile investment that I used to link my study participants to available material support and treatment referrals. For instance, towards the end of my study, I was approached by the MSM sex worker group to assist one of them get back on treatment. This client had stopped taking tuberculosis and HIV treatment and had been struck from his clinic's rolls, and his health was deteriorating. Using my good relations with health providers and peer mentors in KNH, the client was restarted on treatment for both HIV and TB. In Kibera, I referred my needy participants to HAKI for material support such

as foodstuffs, school uniforms, and tuition fees. HAKI's support group received food donations from USAID and Uchumi super market.

Participant observation

The bulk of the data was collected through participant observation, which focused on group activities and individual lives within and outside support groups. Throughout the my fieldwork I conducted observations, and participated in support group activities including support group sessions (informational, sharing of experiences, bead making, drinking tea, calendar activities, hospital and home visits, and various financial contributions). In all of the groups I observed interactions, activities, discussions and conversations, facilitation, leadership, and power relations.

When I first joined the KNH support group sessions I was struggling emotionally: my brother-in-law had died six months previously and my sister also passed on barely a month before I started fieldwork. I had suppressed my emotions so that I could get on with my research. In the groups I introduced myself as a student and explained my study interests at the first session. In subsequent sessions I simply introduced myself as a researcher while group members performed their ritualized introductions, which included announcing their names, when they found out their HIV- positive status, their current CD4 count, and their experiences. As I listened to group members I struggled to keep my emotions to myself, and I tried to resist the dramatic impact that participant observation of support groups had on me personally. The KNH support groups embraced an open group system, meaning new group members could join already existing groups. Many of the new members' experiences were emotionally laden. Some had lost loved ones, others had been put out of their homes or mistreated, and still others suffered from stigmatization.

Finally, in one session, after my usual introduction, one of the group members asked me to say something more about myself other than being a student researcher. The members wanted me to be open to them, as, perhaps, they were open to me. I agree with Wenger (2002) that it is up to the researcher to figure out whether to disclose or not. I also agree that it is up to the researcher to think carefully about whether, when, and how much to disclose with specific participants (Eder & Fingerson, 2002, p. 228). I felt like I was in a real dilemma about whether to share my personal experience. Yet I could no longer restrain myself from

emotionally recounting the two deaths I had suffered in the recent past. It was very comforting and heartening to hear caring and supporting messages, such as ‘*tumesimama na wewe*’ (Swahili for ‘we stand with you’) from the group members and facilitators. The nurse facilitator added, ‘She is mourning, she needs our support’.

This unanticipated sharing was advantageous to me in three ways: it worked as an emotional liberation for me personally, it increased my status as an insider in the group, and it helped me to understand on a very personal level the importance of empathy, which encouraged me to support people emotionally the best I could. Later, in the male sex therapy support group, a new member wanted to know my HIV status and why I was interested in studying HIV support groups. Before I could reply one of the members who had witnessed my emotional unburdening responded on my behalf, ‘She is a student. ... She is not HIV positive but she is very affected, she is mourning. We have accepted her’.

In KNH groups I observed interactions and power relations among group members; I followed group activities, and observed the interactions; I listened to the sharing of experiences and pieces of advice given, and how support was conveyed; I followed topical sessions whenever they were offered and took field notes; I served and I was served tea and snacks; I participated in prayers and singing; and I contributed to various social activities. Outside group sessions I joined in on hospital visits to the sick and home visits to those who had babies. I was invited to and participated in weddings.

At the community-based support groups in Kibera I joined group activities like bead making, contributed to different kitties, participated in advocacy activities, and organized meetings such as World AIDS Day, the annual candlelight memorial, and street activism events. I participated in street demonstrations at various foreign embassies to demand sustainable HIV funding and at Kenya’s Ministry of Health to demand that they keep their HIV funding promises.

I joined the MSM sex workers group at ‘Freedom Corner’ three times a week, participating in various informal discussions and conversations over drinks, and contributed to their social support kitty. Usually after the group session in Kibera or at KNH, I ‘city-hopped’ (took the city-hopper bus) and met up with the MSM sex workers who met every day during *Mututho* time.¹⁴ I participated in their activism events including ‘Mr. Red Ribbon’

¹⁴ ‘Mututho time’ refers to the time when bars may operate as stipulated in the Alcoholic Drinks Control Act of 2010. The law was proposed by Mr John Mututho, a former Member of Parliament for the Naivasha constituency. The bill aims to limit alcohol consumption.

(this is an annual event for MSM sex workers in Nairobi) and the International Day to End Violence against Sex Workers, and in ad hoc processions agitating for sex workers' human rights. I was called upon to offer counselling and advice to some of the group members who had defaulted on ARVs.

I also made a point of visiting at least two members from each support group included in the study outside of the group settings. Some invited me into their homes, workplaces, and social places. With others, I invited myself to spend time with them, particularly in their homes. Sometimes I accompanied support group members or group facilitators to visit sick members in their homes. I found encounters with bedridden patients to be psychologically disturbing and emotionally draining, and the group counselling skills I was gaining from attending support group sessions often proved helpful in these contexts. With the homeless male sex workers, a typical day involved spending time on the streets and other places they frequented, and then hanging out at their evening meeting point, Freedom Corner, and occasionally other work places. These occasions often led to the men sharing their traumas with me. They seemed to experience some relief, unloading the emotional burden they had borne alone for so long. But it was generally emotionally draining for me and often took several sessions on a number of days.

Spending time with participants proved important for observing patterns of behaviour and interactions in different contexts. It also allowed me to witness how they navigated care and support in everyday settings. The informal conversations I had with participants during these visits, often as we walked about town, paved the way for later in-depth interviews and life histories.

Conversations

I engaged in conversations with various degrees of formality (Kottak, 2002). Informal conversations were open-ended dialogues prompted by individuals or groups or me. These included chats that kept up rapport and allowed for prolonged discussions. Before and after structured support group sessions and home visits, and in other meetings I engaged group members in conversations on various issues and, particularly if I initiated them, I focused on seeking clarification or getting more insights into happenings in and out of support group spaces. Informal conversations touched on a wide range of issues such as politics, the

economy, and social life, and I used these to keep me informed about what was going on. Whenever possible I introduced the topics of support groups, care, and support. While it was not possible to simultaneously conduct observations and participate in informal conversations during structured support group sessions, I could do this easily during community-based support group meetings in Kibera, which were unstructured. Outside of support group settings, conversations took place anywhere comfortable in terms of confidentiality for participants

In-depth interviews

I began conducting in-depth interviews after a few months of participant observation and conversation. I asked the interviewees to identify a place suitable for them; in Kibera, participants' homes and support group venues were preferred. At KNH, the peer mentors' office was preferred. For MSM sex workers a restaurant next to Freedom Corner was preferred, and if the restaurant was very noisy, participants would arrange with the hotel management to use a poorly lit but quiet room upstairs.

During in-depth interviews, particularly with MSM sex workers, I realized they often provided socially desirable responses, especially on issues to do with condom use. Although I told them there were no right or wrong answers and that I only wanted to hear their experiences, when topics related to HIV prevention were broached, the atmosphere differed from the usual informal conversations and respondents seem to become uptight. To counter this I adopted a feminist conversational method of interviewing (Merrill, 1999; Kamau, 2009) to encourage them to relax and open up to sharing their life experiences without worrying about the right or wrong answers. In this conversational technique I utilized open-ended questions to elicit life histories and encouraged the interviewees tell their own story using prompting techniques and occasional probing questions. This approach seemed to work and the socially desirable responses shifted to more individual experiences. In-depth interviews were also emotionally draining, as they sometimes veered more towards counselling. Sometimes it took days to complete an in-depth interview. I found that the participants were very wounded in various ways. Feeling like I had opened a can of worms, I sometimes struggled as I offered a listening ear and tried my best to maintain a line between being researcher and acting as a social worker or counsellor.

Walking sessions

On Saturday afternoons, after KNH support group sessions, it was common for group members to congregate in the doctors' parking lot, exchange pleasantries, and take a 30 to 45 minute walk to Nairobi's downtown where they caught buses home. Along the way, groundnuts and roasted maize were often bought and shared as members caught each other up on their day-to-day lives. These journeys were a kind of 'walking session', an extension of the just-ended facilitator-led support group sessions, which were commonly evaluated and discussed on the walks. Sometimes peer mentors and, less often, guest facilitators joined in the walks as well, but as participants. In essence walking sessions were 'support groups without walls'.

Unlike the pensive atmosphere of the KNH support groups, the walking sessions were lively. Participants humorously and explicitly discussed issues they found interesting and contradictory in the support group sessions, particularly issues that generated different opinions between facilitators and group participants. They also discussed new information, social realities of living with HIV, and the issues that they found difficulty in sharing during the facilitator-led sessions. Such issues included reproduction, safe sex, over-the-counter drugs, alcohol consumption, and relationships (among youth). In one instance during a KNH discordant support group session, a member lamented about his HIV-positive wife running away and leaving him. A nurse counsellor tried to encourage the man to move on with life but he was adamant that he wanted his wife back and wanted on how to go about it. Three HIV-positive men in the group were very quiet. Later, I was surprised during the walking session when these men discussed this issue, and especially when one of them observed, 'That man who is HIV negative is very stupid. He should be very happy that the woman has gone away. How can you follow an HIV- positive woman when you are negative?' The other added, 'It is just that we are HIV positive. But if I was HIV negative and my wife was positive I would take off. How could I allow myself to enter a hole [vagina] that has the virus?' When he finished everyone, including the peer mentor accompanying us, laughed as they reflected on the conversation between the man and the nurse.

In facilitator-led support group sessions some of these members were apprehensive and passive. These same people actively participated and were very vocal in the walking sessions. Having gotten to know one another, the members were often more aware of what was going on in each other's lives than were the group facilitators. Information that was

intentionally withheld in the group sessions was commonly discussed while walking; sometimes conclusions drawn based on what was practical in their lives deviated from the expert advice promoted by nurse counsellors in support groups. Over time, the walking sessions made me question the limits of sharing in support groups. Were support groups providing an atmosphere for unreservedly sharing experiences and receiving support as they claimed to do?

Walking sessions became an important, humorous research space where support group participants reflected what they had discussed in support groups. Sometimes other social issues (weddings, funerals, work, dating) not directly related to HIV were also discussed during walking sessions, which also provided a broader frame for understanding their lives and limitations of support groups. For me, the walking sessions proved useful for clarifying information, learning about the ways that group dynamics shifted in different spaces, and getting information that was not shared during facilitator-led groups. Walking sessions were also an important space for eliciting different perspectives on interactions, power relations, and knowledge. I also recruited participants for in-depth interviews and life histories from the walking sessions.

Focus group discussions

I conducted eight focus group discussions in the last two months of the study. Although I had planned to have at least one focus group discussion with all the support groups in my study, for the adult support groups, it was evident that most of the information had been captured in either support group sessions, walking sessions, or informal conversations. However, the focus groups were helpful in getting clarifications, and more insights about issues not well captured by the above techniques. One focus group with the male sex workers was very valuable in helping to clarify issues and for getting new insights about issues that had remained hidden, particularly regarding safe sex practices.

Focus group discussions with Kibera community members helped me to understand better how social support arrangements had changed over time, especially prior to and after the availability of antiretroviral treatment. In Kibera I conducted six focus groups: two with HIV-positive men, two with HIV-positive women, one with HIV-negative men, and one with

HIV-negative women. These were men and women who were not participating in support groups at that time.

Life histories

To gain more insight into the care and support functions of support groups, I closely followed eight PLHIV talking about their lives, in a combination of conversations and interviews. I spent some time with them. This involved a recollection of their experiences, particularly their lives with HIV, although we did not talk exclusively about HIV. I observed their activities, and we also discussed social, cultural, and economic aspects of their daily lives. This involved moving away from support group sites to following them in their homes and diverse social hangout places, and did individualized walking sessions with them as well. We also communicated through mobile phones.

Media review

I asked two well-known HIV activists who plan to write historical memoirs about their involvement in the Kenyan response to AIDS for suggestions regarding publications on the role of Kenyan HIV activists in launching and developing support groups. Both referred me to national newspapers, which led me to visit the main media houses in Kenya, including the libraries of the Nation, the Standard, and the Star media groups. The Nation Media Group particularly devoted considerable coverage to HIV-related issues in their newspapers (both online and hard copy) dating back to May 1990, when there were stories about the first Kenyan to publicly declare that he was HIV positive. They also published reports about the first official HIV death, as well as the early establishment of groups of people with HIV banding together to support one another, fight stigma, and raise awareness about HIV. The media was also very essential on coverage of public moral discourse on homosexuality and sex work in Kenya. Although I did not aim to complete a formal analysis of media coverage of HIV, the newspaper archives provided significant background information for this study, and especially for Chapter Three and Chapter Seven of this thesis. The *Daily Nation* (published by the Nation Media Group) and the *Star* also provided important coverage on public debates around homosexuality and sex workers that were circulating at the time of the study, as did Kenya Network Television (KTN) and Nation Television (NTV).

Ethical clearance and social license

Dealing with different study settings and populations required different approaches to negotiate initial and sustained access to research spaces. The research permit for this study was granted by Kenya's National Science Research Technology unit, a department of the Ministry of Education. Kenyatta National Hospital/University of Nairobi (UON) Ethics and Research Committee gave ethical approval.

Protected space and staying longer

Although these permits and approvals were an important first step in helping me to gain access to the spaces where I conducted my research, they did not require people to participate in my study. Upon presentation of the research and ethical approvals to KNH's acting deputy director of clinical services, I was given permission to proceed with the research. When I went to the Gynaecology and Obstetrics Department, the nurse-in-charge referred me to the department head, who also happened to be KNH's HIV and AIDS Coordinator. The coordinator told me I could not conduct the research at KNH unless he approved it, telling me: 'The topic you are dealing with is very sensitive. I have to protect KNH HIV clients'. He requested for my research protocol and a detailed sampling procedure. While these the issues of concern had already been addressed by the ethical committee, he argued the KNH/UON ethical and research approvals did not offer enough protection for the hospital's HIV clients. Fortunately, he quickly approved the protocol; two days after I gave him the protocol he granted permission and wrote supporting letters to the relevant department heads, which I presented to them in person.

Kenyatta National Hospital is a hierarchical institution, so once I had approval from the HIV and AIDS coordinator, most staff welcomed me. Upon showing the letters, I was granted permission to directly access the support groups. One nurse-in-charge took my letters and then introduced me to other nurse counsellors and peer mentors saying, 'This is a researcher. She has been given permission to study support groups. Here are her letters. Please make sure she goes to support groups'. The support group facilitators then invited me to join support group sessions. Upon my first visit to each group, the facilitators gave me time to introduce myself. I introduced my study interests and procedures and sought the group's

consent to include them in my study. I explained about confidentiality in detail and sought consent regarding how and what I could record during sessions. I was not given permission to use a digital recorder during sessions, but was permitted to take notes. In a notebook, I recorded key issues and persons to follow up with. Following each session, I sat with a peer mentor who had attended the session who would help me to work out more detailed field notes. When an issue was not clear, I sought clarification from the pertinent individuals. For the men's sex therapy group, which I considered extra-sensitive, I asked the peer mentor to ask for consent in my absence before I joined the group, even though I was familiar with the majority of members who also attended the KNH mixed-adult groups.

As an ethnographer, I spent more time at the hospital than most outside researchers. My long-term presence seemed to trouble the nurse counsellors. They were confused about why my research was taking so long when other studies only took a short time. In my ninth month observing the KNH health care workers' support group, a nurse counsellor observed, 'You have been here for a long time. We do not know what you are taking away [from these meetings]'. A peer mentor responded, 'she is trying to understand how support groups work', and I then explained that in-depth ethnographic research commonly spans a year or more.

On another occasion, another nurse counsellor said that she felt I had gathered enough knowledge to facilitate a support group session. On this particular Wednesday afternoon, the group members had arrived for the session, but the nurse was busy and the peer mentors who usually co-facilitated group sessions had not shown up. The nurse told me I should facilitate these groups. I explained to her that this would compromise my position as researcher, and that my position would also undermine my ability to facilitate a support group session. I also pointed out that my ethics clearance did not allow me to facilitate groups.

'What have you brought for us?' Expectations of assistance and recompense

My position as a researcher working on HIV, a heavily funded research subject, proved an important challenge. Tensions between obligations to informants and/or reciprocity and professional responsibility in Kenya have been documented by Nyambedha (2008) and Onyango-Ouma (2006). In examining ethical dilemmas related to conducting social science research in resource-limited communities, Nyambedha highlights the 'delicate balance between research and ethics, the expectations of the study population, and the community's

vested interests' (2008, p. 771). Because HIV was commonly associated with significant donor funding, it took a great deal of effort to convince my study participants, many of whom lived in relative poverty, that academic research on HIV support groups would bring me no financial gain. Similarly, it was difficult to convince people that my research would not bring them any funding. This was particularly challenging in Kibera, a community that had received massive funding, some of which had gone directly into the hands of the support groups I wanted to study. I also recorded claims of exploitation by other researchers who had reaped personal gains (Onyango-Ouma, 2006).

During this study, I was asked 'What have you brought for us?' over and over again. My previous research experience had not sufficiently prepared me to deal with the material expectations of the participants. I had never before been asked what I had 'brought' participants. I could see that research participants had learnt to request or demand funding or material assistance. My research did not bring significant material resources to participants, but, recognizing the poverty they were subjected to and their generosity with their time and expertise, I brought milk and bread whenever I visited study participants in their homes.

During the support-group mapping exercise, I let the KIPOTEC chairman lead the introductions. He introduced me as '*Huyu mwanafunzi mtafiti na hana pasa*' (a student researching support groups and one who did not have money, in Swahili). Somehow it was discomfoting. A couple of days later I asked him why he stated to the groups that I did not have money. He replied:

People in Kibera think any HIV project has money. You know they say HIV money is their money and that people use them [HIV positive people] to make 'lots' of money. They can even refuse to let you visit their groups because you did not give them money. Some can be expecting money from you. I have to make that clear to them so that they do not ask you for money.

The chairman's declaration did not deter some people from asking for money and help, especially people from splinter groups who were looking for funding opportunities. A key informant from one PLHIV organization blamed such materialistic expectations on the organizations that led interventions in low-resource communities:

The partners were after numbers, meeting their own objectives and goals. Because you want to get people tested and you give them 100 shillings (1 Euro), you will get many people coming including those who already know their HIV status because they want that 100 shillings. ... Because you go the community and tell them you want to have a workshop to

train them on community-based care, they will ask how much you are going to pay them.

They do not see the benefit of attending the training other than money because they have the perception that you, having come to train, you have been given money to 'support' them.

Indeed, this was my experience during my first couple of months in Kibera. Immediately after I left my first meeting with the KIPOTEC chairman, held in an open-office setting, a volunteer followed me to tell me that they did not trust the chairman. While this developing scenario was good for research, I must admit I felt disturbed by this act.

During that visit, I had left my phone number in the KIPOTEC visitors' book, as I had been requested to write some remarks and sign the book. One morning, I received a call informing me that there was a crisis in Kibera's support groups and that I should go to meet with the support group leaders. This sounded like a great opportunity for my study. I immediately went to the venue where I met a strange man who, after introductions, told me, 'people are wondering what Emmy has brought them'. He led me to a social hall where a training of support group leaders by AMREF was going on. The KIPOTEC chairman was there, and he introduced me to the group. This gave me the opportunity to explain my study and talk about academic research. The chairman added he was interested in the research because, as KIPOTEC chairman, he wanted to know why groups were inactive. When I finished, I was asked a couple of questions about money matters. One leader observed that people and organizations 'use' support groups in Kibera to make a lot of money while the groups do not benefit. Another asked, 'Why would you suffer working in Kibera if it was not for money?' One more asked me, 'How can you conduct research on support groups without any plan for funding them?' Apparently, as was with the case of the volunteer above, some thought the chairman was benefiting financially and was not telling them the truth about my study. Undeniably, these were very logical questions, I thought. Given the massive funding and the levels of corruption reported, and their experience watching a few PLHIV enrich themselves, their concerns were valid. And it was true that I was gaining a benefit by collecting data that would allow me to obtain academic credentials. At this point I thought the groups would not agree to participate in my study. I was wrong. Those I approached did accept, and some of those that I left out came asking why I did not select them. This provided an opportunity to explain the selection criteria.

Money matters within support groups

Once community-based support groups allowed me to include them in my study, I found out that money issues were often more sensitive and attended to more passionately than were HIV issues. Three support groups I selected to research in Kibera conducted their group meetings in two segments. The first segment was dedicated to various activities including HIV discussions and the second focused on money matters. One of the groups, which employed a hybrid of health facility and community-based support group ways of conducting support groups, granted me permission to observe both segments, after some discussion. In the second segment of the meeting, the secretary of the group opened a records book and asked members to make 20 KES (2 eurocent) contributions towards a group savings-and-loan (GSL) scheme, and then two types of merry-go-rounds: one for 20 KES and the other for 10 KES. There were heated arguments and insults about the merry-go-rounds. Some members accused the group leaders of favouritism and taking their money, while others complained about some members who disappeared after they got money.

In two other groups, I was only allowed to attend the first segment, which did not reveal much. I was treated with suspicion. Once the segment was over there was always an awkward moment of silence, though I could read the message on their faces: 'please leave'. Seeing I was not leaving, one of them would gather the courage to tell me the support group session was over and they had other private group matters to discuss. Realizing the sensitivity around money, I then negotiated access to the second part of the session. I had to explain my study over and over again.

In another group, as we waited for leaders to arrive, members bitterly complained about the leadership and accused their leaders of enriching themselves by embezzling GSL contributions, selling the group's plot of land, and taking donor funding meant for the group. With them, I negotiated permission to participate in the second segment. When the session began, one of the leaders was in attendance, and, as usual, at the end of the first segment the leader told me the meeting was over. However, one of the group members said it was very important for me to stay for the second segment to learn more about how groups handle money issues to fully understand how support groups work. Publicly confronted with this rationale, I think the leader had no choice but to let me stay. Given such anxieties and expectations, building trust with different communities, institutions, and individuals was an integral part of this research.

In the MSM sex worker group, John, my gatekeeper, introduced me as a student. This seemed to work well. In the spirit of reciprocity we offered each other drinks, but since I was a student, and therefore did not have money, they challenged me to seek out funding. I asked them why they did not seek out funding themselves, and they said that they did not know how to write such proposals.

Being legal in an 'illegal' space: working with MSM male sex workers

Imagine you are enjoying the company of a group. Then one day you are told that your meetings are not licensed and are therefore illegal. And so is the group you are studying.

My journey into the group of MSM sex workers that I studied began three months after I was told about the group. As I mentioned above, I met John, the director of HOYMAS, coincidentally on the last day of the 2011 HIV Biennial conference in Kenya. John brought me to a research dissemination workshop, after which participants were treated to an early dinner at the hotel's restaurant. During dinner I met three well-groomed men in their late twenties. Unlike sex workers, who prefer to use sheng language¹⁵, these men used English. I introduced myself and my research interests. They introduced themselves as 'gay men working for Ishtar', a male sex work organization run by gay men. Through these men, I was introduced to Ishtar and LGBT staff, and I was then invited to attend upcoming activities. In such activities I was, again surprisingly, introduced by Ishtar's director as 'an ardent supporter and a friend'.

Three weeks after the research dissemination workshop, John invited me to an MSM sex workers' training. By this time I was not surprised, but amused as John introduced me: 'This is Emmy, a friend of mine who is studying in Amsterdam', and the training participants responded in chorus, '*huyu ni wetu*' (this one is ours, in Swahili). It was amazing how being John's 'friend' and my connection or association with Amsterdam fast-tracked a degree of 'social license' and helped me build rapport with this group. By the end of the second day's session, they invited me to join them at their daily meeting place, Freedom Corner, and gave me directions and meeting times.

¹⁵ An ever-evolving language coined mainly from Swahili and English, sheng also borrows from other Kenyan ethnic languages. Originally popular among underprivileged youth in Eastland's section of Nairobi, the language has spread across social classes among urban youth.

Three weeks later, on a Monday at seven in the evening I made it to Freedom Corner. I found seven MSM sex workers when I arrived, and 12 more joined us as the evening went on. My connection with Amsterdam, a gay-friendly city where homosexuality is 'acceptable', and the Netherlands, a progressive country on homosexuality (Keuzenkamp et al., 2007), helped me to be seen as one who had sufficiently undergone 'gay friendly' enculturation. At the LGBT workshops and activities I attended, I was almost always introduced with the phrase: 'This lady is our ardent supporter' or 'This lady is really supporting us'.

Amsterdam mattered. During my early visits, the word 'Amsterdam' worked wonders, helping me to establish rapport and build trust. I was nicknamed 'Emmy Amsterdam' and, even though I was naïve about gay identity issues and homosexual practices, research participants often wanted to talk to me about gay men in Amsterdam and their activities. They asked many questions for which I had no answers. They asked whether I had met gay people in Amsterdam, the difference between gay men in Kenya and Amsterdam, whether I had seen men sex workers in Amsterdam, and if I could get them 'white men' partners or clients. To my amusement, one proposed I become their advertising agent in Amsterdam connecting them with clients or long-term partners. They did not know that they were the first group of MSM and the first male sex workers I had knowingly come into contact with. Their questions elevated my curiosity and eagerness to get back to Amsterdam to look for gay men.

After some time, Amsterdam was dropped from my name and replaced with 'ardent supporter'. My ethnographic approach turned me into a supporter and an insider in their eyes (and I was). Similarly, our conversations gradually shifted to their personal experiences of being gay and doing sex work in Kenya. I was invited to all of their activities including meetings and street demonstrations or processions. In such activities, I was introduced as simply their supporter, never as a researcher. Often I was the only 'outsider' present, and I was the only researcher present at every activity. Their acceptance of me struck a chord: I felt privileged.

Researching sensitive issues

Much has been written about researching sensitive matters that involve privacy and may trigger deep emotions among research participants. Kamau (2009, p. 72) noted HIV/AIDS topic is sensitive because it is surrounded by silence, ignorance, secrecy, stigma, and discrimination. De Klerk (2011, p. 17) in her study, *Being Old in the Time of AIDS*, notes that researching AIDS requires bringing into the open what is often hidden, private, and painful. Similarly, Tamale (2011) has noted that sexual issues are often taboo and sensitive topics. As private affairs, sexual issues are surrounded by secrecy and silence in some communities in Kenya (Ahlberg, 1994). Homosexuality and sex work practices that are considered 'deviant' and criminal acts are also surrounded by stigma and secrecy. A few studies have also noted the ways that research on sensitive issues can confront the researchers as well, particularly when they present people's private accounts in the public domain (De Klerk, 2011; Kamau, 2009).

This research touched on four sensitive topics: HIV, sexuality, homosexuality, and poverty. However, the degree of the topics' sensitivity varied among study participants. It is important for researchers to contextualize sensitivity as well as the how sensitive issues are presented. Sometimes what I thought would be sensitive turned out not to be sensitive to some of the research participants and vice-versa (McCosker, 1995). For instance, I thought HIV was more sensitive than money matters, but as I found when I tried to gain access to the second segment of support group meetings, money matters were more sensitive than HIV and sexual issues among Kibera residents. Sexual orientation, sex work, and HIV-positive status were more sensitive than poverty among MSM sex workers, while HIV-positive status and sexuality was more sensitive among those attending KNH support groups, especially among the middle class.

Sometimes sensitivity changed with space and time. For instance, in the beginning of my research I found it very strange when humour was used in discussing painful experiences. Livingstone (2008, 2012) in her work in Botswana noted the use of humour in painful experiences. I was surprised when one group member humorously recounted a rape ordeal while the rest of the group members laughed. I was also puzzled when some group members humorously imitated how they struggled physically in walking to their first support group sessions. In another instance I was in the company of two MSM sex workers in a taxi to Nairobi's central business district and as we crossed Nairobi Central Park one of them

intimated to me that the place was very dangerous and went on to recount being raped by two men in the park. I was very surprised when he said that one of the two rapists was 'very sweet': '[I]t was 8pm. I was alone walking through Uhuru Park [Nairobi Central Park]. Some two men smartly dressed in suits followed me, grabbed me, and raped me. The second one to rape me was very sweet, I enjoyed it'. I was stunned when another male sex worker humorously told me how some male sex workers enjoy being raped, and the therefore look for opportunities to be raped.

While humour and laughter were commonly deployed as coping mechanisms in Kibera and at Freedom Corner, the KNH support group members were often overcome with sadness when members narrated an ordeal or difficult experiences. Crying and sobbing was very common. However, my presence in those sessions also played an important role in diffusing the sensitivity of certain topics, which made them easier to discuss later during follow-up interviews, informal conversations, and walking sessions with support group members.

As writes Kamau (2009), research analysing sensitive issues often fails to capture the challenges faced by the researchers. I had not predicted how challenging it would be to engage and disengage with the individuals among whom I conducted research. It was often difficult to maintain different kinds of relationships with study participants. It was a steep learning curve that required me to be prepared physically, socially, and emotionally.

The importance of this became clear to me when attending a men's sex therapy group and when conducting research with MSM sex workers as a heterosexual Kenyan woman. I was overwhelmed by the men's sensitivity to my presence in the groups and by the impact of sensitive issues on me personally as I contemplated and contended with broader cultural norms and values (McCosker et al., 2001). I hail from a community where it is culturally and socially unacceptable for men and women to discuss sexual issues in the same setting, particularly when the topic turns to what are considered sexual dysfunctions. Secondly, I am a Catholic, a religion that does not condone homosexuality. I found myself at a crossroads with my cultural, social, and spiritual value systems. Yet, I was aware it would be naïve for a researcher not to study a group due to their religious value system. I knew if it was hard for me to set these norms aside, it was likely even more so for them. As such, I was humbled when they accepted me as a researcher, confidante, and sometimes friend.

I was incredibly uncomfortable during my first couple of sessions as I listened to men share their experiences with sexual dysfunction. The group was co-facilitated by a male peer

mentor and a female nurse counsellor, but on several occasions a male counsellor replaced the female nurse counsellor, leaving me as the only female in the room. Simply being present helped to dissolve my own unease. I quickly learnt to go with the flow of the group members: laugh when they laughed, remain expressionless when everyone was quiet and pensive. Based on my observation of body language, I deduced that many of the men in the group were also apprehensive about talking about these issues in general, and with me specifically. Some literally looked down while sharing their problems in group sessions, others avoided eye contact, especially with me, when explaining sexual dysfunctions or discussing sex acts. The worst moment came when a male clinician was teaching how to enhance sexual pleasure and he demonstrated with his hands. Sometimes I felt like walking out, but as a 'genderless' researcher I hung in there, going with the flow.

A guest facilitator/nutritionist also seemed to find it difficult to ask sensitive questions in the presence of a woman. He first smiled sheepishly, seemingly suggesting I (a woman) should walk out. Realizing he was uncomfortable, a member of the group who probably read his dilemma observed, 'We have accepted her. She is a researcher who is learning. We do not hide anything from her'. Yes, I was a researcher, but I remained a woman in their eyes. My participation was not only limited to listening to their experiences, as I was often asked to discuss my experiences as a woman and to offer insight into women's perspectives, including what women prefer sexually.

It took me a little longer to adjust to working with MSM sex workers who from the beginning freely, casually, and explicitly discussed their sexual encounters including enjoyments and disappointment with clients. Initially some would caution others about the language used in my presence. Much of my research with them concentrated on the happenings at Freedom Corner and I gradually became used to seeing them working in that domain. My 'days out' with some of them, however, initially took me by surprise because I had not considered the fact that as sex workers, they might work anywhere and might quickly take up an opportunity to make money. They seduced men on the streets, in the restaurants, and at the shops or supermarkets we visited. I did not see this as a bad thing per se, but as an outsider I found it unsettling.

One afternoon during a day out, we passed through a shop to buy a few items, and on our way out of the shop, he, with a big smile, told me he had seduced the owner of the shop. What? I thought we were shopping. With time, I learned to see these as interesting opportunities for observation. As the only female in the group I also became the 'body spray

tester' whenever the members went shopping. Since most of them preferred femininity, I was asked to try on body sprays to make a decision on whether the body spray was good for male clients. Going through these experiences, although unsettling, helped me to grow comfortable enough to be able to discuss almost anything with them eventually. While I generally agree with Finch's (1984) suggestion that women researchers often work better with women because they share similar experiences, I found that despite the initial challenges, I had an easier time establishing rapport and working with gay men especially. The men I researched treated me like I was one of them. I was never worried about hanging out at the bar till late in the night with them; they respected me and ensured I was safe. Discussions on sexual issues were normalized; we could discuss just about everything having to do sexuality as well as personal issues.

My research also sometimes caused rifts in my social networks. After excitedly talking to my friends about my research with MSM sex workers at a bar in Nairobi's River Road, I received several negative and discouraging comments. One bluntly told me, 'I cannot do the work you do!' A number of my friends asked: 'Are these the only people you can study?' Most often, I had to explain that I was *studying* MSM sex workers in response to the question, 'Why are you supporting them?' Some even questioned my sexuality. 'If you associate with them, you must be like them'. After listening to me describe my work, a friend of mine, a lecturer at a regional private university, invited me to an upcoming international social science research conference but asked me not to present on MSM sex workers. I became what Plummer (1975, p.4) referred to as 'morally suspect'. These reactions made homophobia real, and increased my passion to study this group. It became very clear to me that omitting this group would not only be naive of me as a researcher but also would undermine the importance of understanding the connection between HIV, social support, and marginalization.

While I was consumed with these homophobic reactions and my own passion towards this group, naively, it never occurred to me this group and their meetings were illegal. I had no idea that activism activities like an 'Ending violence against sex workers' demonstration, which took place in the presence of the police and in which I had participated, were illegal. A fight broke out during the 2011 Mr. Red Ribbon event, with over 300 MSM sex workers, three NGOs representatives, representatives from three UN agencies, four lesbians, and a NASCOP officer in attendance. The NASCOP officer took to the podium and made the following announcement: 'Stop fighting. You know this meeting is illegal. We are not

supposed to be here. All of us will be taken in by the police'. It was only at this point that I realized I had all along been in an illegal space and began to question my personal safety as a researcher. At the same time, however, I also wondered what a government officer and UN and NGO representatives were doing in an illegal space. I discussed my concerns with my Kenyan supervisor, who assured me I had no cause for alarm because I had received approval to conduct research on HIV support groups, and there were no exemptions that excluded MSM or sex workers.

Conclusion

Studying support groups requires a great deal of flexibility and sticking to a predetermined methodology can cause one to overlook important aspects of support groups. An open-ended methodology proved fruitful for this study. The mapping exercise became a critical research technique for understanding the typology of the groups and was helpful in locating groups in the study area such as the MSM sex workers' organic group. Studying support groups also means being more than a researcher, as you take on other roles of a social worker or a counsellor, and these roles, I would suggest, become part and parcel of the study's methodology.

As an ethnographer, I walk into the lives of research participants, invading their space and privacy for months or years. They allow me. The desire is to maintain researcher-researched neutral relationships while balancing professional ethical responsibility (informed consent) and moral obligations (Nyambedha, 2008; Onyango-Ouma, 2006). Being in the field longer means you are no longer a 'stranger' to the community you study. You follow them, hold conversations with them, and interview them: you become a part of their lives. But again, as an 'outsider' they confide in you. They too study you: their sociability and efforts to get closer or friendlier to you blur researcher-researched boundaries. You are likely to become more than a researcher. This was noted across all socioeconomic classes but from different perspectives and for different reasons. The middle-income group members approached me for information on over-the-counter drugs (even after I made it clear that I was not a medic), accessing health services, and issues related to their sexual lives and reproduction. They also sought emotional support.

Although it was difficult in the beginning to sit among men and discuss their sexual lives or to hear the emotionally challenging stories people shared with me about sickness,

poverty, and betrayal, in time I embraced the research and also began to benefit from it (Hutchinson, Wilson & Wilson, 1994). In addition to the emotional healing I experienced from participating in group sessions, I felt a sense of purpose as I offered a listening ear, advice, and information to others, while also offering support, acceptance, and hope.

In an economically challenged community it is not easy to strike a balance between ethical responsibility and moral responsibility: I found it difficult to fail to act on the many demands and favours requested (Onyago-Ouma, 2006). As Elliston (2005, p. 30) asks: 'Why should research subjects tolerate us? How do we manage to plug away at fieldwork for months and years in what are oftentimes unfamiliar and stressful social contexts?' These questions resonated with me. During my fieldwork I came across many people with economic challenges. I felt I had to help out. Although it was not much, I also offered material assistance when I could. As noted by Lee (1993), researchers are morally compelled to find a way to deal with the problems and issues raised or encountered when doing research; you cannot ignore or just observe others' problems. Maintaining good relations with institutions in your research site is very important. I referred study participants to CBOs, NGOs, and health facilities for assistance. Sometimes, I felt I had crossed a boundary from researcher to an outreach worker, yet such opportunities were very productive to the research because they helped me to learn more about the way HIV intersected with economic and emotional vulnerabilities and, consequently, to better understand the important role support groups played in addressing these vulnerabilities.

CHAPTER 2

THEORIZING COLLECTIVE CARE AND SUPPORT

Background

HIV is a biographical disruption, unsettling the physical, economic, cultural, and social life of a person. Although physical and psychological challenges may be encountered before a diagnosis is made, enormous psychological and emotional consequences of receiving an HIV-positive diagnosis has been demonstrated repeatedly (e.g., Kyakuwa, 2011; Mello et al., 2009; Zhou, 2007; Bronsard et al., 2004; Chippindale & French, 2001; Burgoyne & Saunders, 2000). Additionally, learning that one is HIV positive may affect a person's identity or life purpose (Mello et al., 2009; Zhou, 2007; Bronsard et al., 2004; Whyte et al., 2004; WHO, 2003a; Kalichman et al., 1996). For most PLHIV, significant mental work is required to adjust to the new identity and imagine one's life as an HIV-positive person.

The increasing availability of effective antiretroviral treatment has allowed people to live longer with HIV, and many PLHIV have contend with lifelong care and support needs related to day-to-day living with the disease (McGrath et al., 2014; Marsland, 2012; Kyakuwa, 2009, 2012; Russell & Seeley, 2010; Prince, 2009; Whyte et al., 2004). Daily struggles may involve arranging nursing care, taking complex essential medicines, increasing nutrient intake, managing extended clinical care, adopting or rejecting certain behaviours, managing sexual and reproductive desires, and managing stigma as well as social phobia (McGrath et al., 2014; Kyakuwa, 2009; Mello et al., 2009; Fuller, 2008; Bronsard et al., 2004; WHO, 2003a; Zhou, 2007; Burgoyne & Saunders, 2000). *Living* with HIV, rather than *dying* from AIDS, can actually expand the social, psychological, and economic burdens of PLHIV. I emphatically agree with Whyte et al. (2004) that until and unless a cure is discovered, HIV requires a lifelong care and support system.

Living longer lives with HIV demands long-term management, including extended clinical routine monitoring, treatment of opportunistic infections and side effects, various tests (such as CD4 and viral load), and increased nutritional demands (McGrath et al., 2014; Kyakuwa, 2009; Mattes, 2011; NASCOP, 2008a). All these require resources (money and time), which means PLHIV often worry about their reduced productivity and the struggle to meet their essential needs (Le Marcis, 2012; Marsland, 2012; Kyakuwa, 2011). While HIV counselling offered PHIV skills necessary to live on (Burchardt, 2009), life does not return to

normal on treatment, especially sexual and reproductive life (Scanavino & Abdo, 2010; Crum et al., 2005; Moreira et al., 2001; Tindall et al., 1994); worries about (re)infection, stigma, disclosure, safer sex, and mother-to-child transmission are common among those living with HIV (Mattes, 2011). They worry about sexual and reproductive issues, and about masculinity, motherhood, and sexual identities. Among the participants in this research, sex – as the main mode of HIV transmission – appeared to be a complex, often negative, and stressful aspect of life.

For more than three decades, HIV has remained a highly stigmatized condition in Kenya. Following Goffman (1963) I see stigma as a spoiled identity that sets individuals or a group of individuals apart from the rest of the population. Even with ARV treatment and more than two decades of HIV education and awareness, reinforced by moralizing discourses of HIV, HIV-related stigma persists in families, communities, and clinical settings (Moyer & Hardon, 2014; Moyer et al., 2013; Mattes, 2011). People living with HIV today in Kenya still worry about disclosing their status; they fear being judged, rejected, or isolated (Moyer et al. 2013). HIV-related stigma does affect social relations and the adoption of coping strategies in many ways (Kyakuwa, 2012; Kamau, 2009. T. Nguyen et al. 2009), and also compromise the mobilization of social support (Kamau, 2009; Skinner & Mfecane, 2004). Friction in social and sexual relationships resulting from and leads to secrecy or silence about their health status, stubbornness, and the refusal to conform to sick role¹⁶ expectations, in turn can provide dilemma and frustrate an individual's ability to get the types of social support needed and desired from existing social support networks (Kamau, 2009; Bronsard et al., 2004). Stigma also compromises access to HIV and other medical services, as well as treatment adherence (Black & Miles, 2002). Paradoxically, HIV-infection can result in social alienation just when PLHIV most need the care and support of others to survive and thrive. A strong social support system is one of the most important resources for practical and emotional support and for coping with the disease (Van Buuren et al., 1992; Rodgers, 1995).

The emergence of HIV exacerbated pre-existing infrastructure and personnel challenges facing the health care system in Kenya. Community-based structures became an important partner in providing care and support to people with HIV and AIDS. In Kenya, as in many places in the world, the obligation to care and support the sick is normatively

¹⁶ Sick role is a particular way of explaining the rights and responsibilities of those who are ill (Parsons, 1951). Specifically in regard to exempt of the usual social roles when one is ill.

assumed to be a responsibility of traditional social support systems –kin – based on notions of reciprocity (Kamau, 2009; Helman, 2000) and entrustments (Shipton, 2007). The role and challenges of family and society in meeting the care and support needs of the sick in Kenya has been well documented (Prince, 2013; Kamau, 2009; Nzioka, 2000). Many people used to and still do fall back upon extended families for care and support in times of prolonged illness. Although the prevalence of kin-based care has indeed declined in Kenya in recent decades in the context of growing urbanization and increasing reliance on the nuclear family, I would argue that family remains the strongest social support system for most of those living with HIV (De Klerk, 2011; Bor et al., 1993; Bor & Tilling, 1991; Iwelunmor et al., 2008; Brown et al., 2010).

Along with Kenya's changing social context, I would also argue that AIDS, the disease itself, has significantly challenged the ability of families to provide the quality of care they would like to offer their kin. Some researchers working in Tanzania have argued that families often fall short in terms of providing care for those with HIV (De Klerk, 2011; Mattes, 2012; Setel, 1999; Dilger, 2006, 2008). Providing care and support to those infected with HIV can be both challenging and stressful. It is physically, emotionally, socially, and economically taxing, leading to some caregivers needing support themselves (UNAIDS, 2011; De Klerk, 2011; Geissler & Prince, 2010; Nzioka, 2000).

Although effective antiretroviral treatment (ART) and counselling has certainly made caring for people with HIV easier, studies by Bronsard et al. (2004) and Whyte et al. (2004) suggest that once a relative is on ART, support providers no longer recognize patients' struggles. PLHIV are no longer entitled to complain, and both economic and social support may be withdrawn or reduced. With persistent requests for support or care, one is seen as burdensome, or seeking to take advantage of their HIV-positive status (Odiwuor, 2000). Yet, people living with HIV struggle to provide for themselves and their dependants, and permanently struggle with managing HIV chronicity including treatment of continuously recurrent illnesses (Mattes, 2012). In these contexts, where patients can no longer rely on family to meet their care needs, people diagnosed with HIV have turned to support groups in which they are both providers and receivers of care and support (Whyte et al., 2004; Odiwuor, 2000).

Previous research with support groups

I first came into contact with HIV support groups in Kibera and KNH at the end of 2003. I was conducting ethnographic research on HIV and infant feeding under the supervision of social anthropologist Dr Saskia Walentowicz in what was known as the Milk Study¹⁷. At that time, HIV was a huge crisis in Kenya and HIV treatment had just begun to be offered in public health facilities in Kenya. Although support groups were not an object of my study at the time, my encounters with such groups gave me an opportunity to observe the sporadic growth of support groups and the changing nature of these groups in terms of their content, meanings, and activities in Kibera and KNH.

During the Milk Study, I came into contact with the community-based Great Lang'ata Support Group in Kibera, and at KNH I met with the prevention of mother-to-child transmission (PMTCT) support group. Both groups were organized to reduce the transmission of HIV from mother to child through breastfeeding. The Great Lang'ata group was made up of low-income women who were receiving formula milk and maize flour from the International Medical Corps, USA. The KNH PMTCT support group consisted of members who were better endowed economically though they also benefitted from the formula milk program. As part of my research, I attended several support group sessions and conducted interviews with group members and leaders known as peer mothers.¹⁸ In addition to free infant formula, porridge flour, and HIV-related information, the support groups provided space for fashioning an HIV-positive identity, fostering empowerment, starting new friendships, networking and, as is the case in Kibera, acquiring material support.

It became apparent to me that HIV meant different things to different people. For those living in Kibera, HIV was entangled with extreme poverty, violence, and dependency on NGOs and philanthropists for basic needs and services. In a sense, HIV exacerbated poverty (Prince, 2013). In this community, HIV and AIDS are an additional problem on top of the already precarious living conditions of people in this community (Collins & Rau,

¹⁷ The Milk Study was the social scientific arm of the Kesho Bora's clinical trial project for the prevention of mother-to-child transmission of HIV. The clinical trial provided pregnant women with Highly Active Antiretroviral Treatment, free formula, and information.

¹⁸ These were women who had previously successfully completed the PMTCT programme. By virtue of their experience, they were to support other women who were on PMTCT to adhere to the infant feeding programme. They also educated women on positive living.

2000). Most adult breadwinners in Kibera rely on petty businesses and casual work, but this was a challenge for PLHIV, as illness incapacitated people physically, socially, and economically.

The influx, then, of HIV and AIDS funding, complete with material donations, was indeed considered a good thing in Kibera. Funding and material donations not only brought hope but also raised expectations. The widespread interest in such donations, popularly known as '*msaada*' (Kiswahili for help or aid), grew within the Great Lang'ata group. Though not initially established to benefit members materially, Great Lang'ata – and support groups in Kibera in general – evolved to be understood by the Kibera community primarily as conduits for donor material support. Being HIV positive provided economically marginalized people with an identity that allowed them to demand much needed material assistance from support groups and other community-based organizations. As the term 'support group' came to signify material support, its association with psychosocial support diminished. This was exemplified in the Great Lang'ata group, which was initially intended as a means of preventing HIV but soon evolved into a *msaada* forum. Formula and porridge flour were distributed after psychosocial and topical sessions, but members did not appear to take the sessions seriously. Oftentimes, most group members arrived just in time for the distribution of the formula and flour. In response, the peer mothers threatened to withdraw formula and porridge assistance to members who were only interested in *msaada*.

I noted that, amongst the members of the Great Lang'ata women's group, the *msaada* mentality was signified by the practice of participating in multiple support groups to find out whatever benefits were available and then sharing that information with others. One time as we waited for a support group session to begin, I sat with group members and listened as their discussions revolved around finding out what *msaada* was available from which support groups, community-based organizations, and NGOs in Kibera and its environs, and crafting strategies on how to access them. The discussions continued on afterwards as members walked home in groups and finalized plans on when and where to meet, which organizations to approach, and which support groups to join. I heard about women criss-crossing support groups in search of material support and using their HIV status to demand such support and opportunities.

I also noted the KNH support group, in contrast, focused more on HIV and AIDS information and psychosocial support. Everyone attended the group sessions that took place before the distribution of formula. The group met monthly in a spacious antenatal care room

and nurses and nutritionists facilitated sessions. Unlike the Great Lang'ata group session, the KNH PMTCT sessions were profoundly emotional. New members cried while sharing their experiences and older members encouraged them with statements like, 'You are not alone', and 'We are all together in this'.

Five years later, while working on the NIH-funded, Multisite AIDS Testing and Counselling study in 2008 and 2009,¹⁹ again in Kibera and KNH, I also came into contact with support groups. In the intervening years, support groups had proliferated, and many people had multiple memberships. James, a KNH support group facilitator, acknowledged the significance of the groups to members in providing HIV knowledge and psychosocial support. However, he decried the shifting conceptual centre of support groups from psychosocial and informational interventions to mere economic ventures in low-income communities:

There is demand for support groups – here in [KNH] we increased the number of support groups to accommodate the [demand]. We also only have people in support groups for a limited period of nine months, and then encourage them to join other support groups in their home areas. ... There are people living with HIV who just walk into any support group; they want to be in every support group. Within Kibera we have a percentage of women who attend different support groups every day. ... Apart from psychosocial support they may expect financial, material support in terms of food, fees for their children, so that is why they are adventurous. ... Some people have converted support groups into gossiping and quarrelling spaces. Some support groups are individuals' personal property – they charge a registration fee; in some of the groups, members are asked to make a 20 Kenyan shilling weekly contribution for subsistence. Those who are unable to contribute drop out and look for other support groups where there are no fees. Some support groups have been turned into merry-go-rounds. ... Support groups can build you [up] or destroy you.

This excerpt illustrates the shifting needs, challenges, and expectations of PLHIV and the potential and the shifting terrain of support groups. ARVs and food, plus other practical needs were essential to survival.

One important change that I noted was that, unlike in 2003 when support groups were

¹⁹ The National Institutes of Health funded the Multisite AIDS Testing and Counselling (MATCH) study was conducted in Uganda, Malawi, Burkina Faso, and Kenya in 2008 and 2009, and looked into the uptake of HIV testing and counselling.

made up of women, in 2008 (after treatment had become available) men were not only participating in support groups but were also running the show. As expert clients, they were paid stipends to facilitate support group sessions. I was intrigued by the transformations that were taking place in these groups, and became interested in studying it further, in particular how care and support were being defined and delivered in support group spaces.

Defining care and support

A great many definitions of care have been advanced, mainly by anthropologists studying chronic illnesses and the elderly (Kleinman, 2009; Mol, 2008; Marianti, 2002). Generally, the anthropological view is that care includes assistance in the practices, activities, or strategies and any other capabilities of managing or coping with illness. These include mundane activities of life (Kleinman, 2009, p. 293) or what Mol (2008) refers to as important practices that make life bearable. Folkman, Chesney and Christopher-Richards (1994) define care as strategies related to managing the primary consequences of illnesses including pain, and secondary consequences of the illness burden. Care may include ensuring access to professional clinical treatment or to information and supporting emotional well-being (Visser, 2005; Marianti, 2002; Helman, 2000). In *Surviving Spouses: Support for Widows in Malang, East Java*, Marianti (2002) challenges us to consider the definition of 'complete care' that includes 'caring for', which is the offering of nursing care, and 'caring about', which is the show of compassion or empathy.

In his book *Social Basis of Community Care*, sociologist Bulmer (1987) defines care as looking after, and effective community care as part and parcel of meeting the needs of the dependent members of society. He stresses the need for both formal and informal care, which he argues are complementary. In her study on HIV among the middle class in Kenya, Kamau (2009) defines care as looking after the sick in terms of nursing activities, accompanying them to hospital, performing household chores, and providing financial support.

According to UNAIDS (2003a), comprehensive HIV care and support include material, medical, psychological, social, spiritual, and informational support for PLHIV and their families. In 2011, from a human rights perspective, legal care and support was added to the list (UNAIDS, 2011). The Office of the United States Global AIDS Coordinator (OGAC, 2004) defines care as the attention or considerations to relieve physical, emotional, spiritual,

and practical suffering. The Kenya National AIDS and STI Coordination Programme (NAS COP, 2008a) defines care as prophylactic medication, treatment of opportunistic infections, improved nutrition, psychosocial support, and the prevention of opportunistic infections through safe drinking water and the use of mosquito nets. This last definition masks other practicalities of care and support required by PLHIV, as social science studies show care and support for PLHIV is more than prevention of physical illnesses.

Due to multiple and shifting needs, care and support for HIV cannot concretely be defined. PLHIV, therefore, should play important roles in defining their own care and support needs. In the larger Kibera community, I found that there were two notions of being sick in relation to HIV: the first simply indicated that a person, though looking healthy, was infected with the virus. In this view, PLHIV are expected to care for themselves, either because the disease had not progressed or because their health had improved. They were not seen as requiring care from their significant others, though in the context of HIV prevention interventions, they were seen as disease reservoirs, 'the dangerous other', and vectors of HIV infection. The first definition – HIV infected, but not sick – complicated things for those who needed care and support despite their improved health. As Jackie, a participant in the MATCH study, said in a 2008 focus group:

My own family has disowned me. I cannot work now and my people have abandoned me. You know, HIV is an expensive disease because of the maintenance required. ... You need somebody to be giving you money. But who can keep doing that all the time? In fact when you look fine and ask people for money, they say you are taking advantage of your condition to get money from them.

The second definition of sick was used for a person who was not physically well enough to care for him or herself, and hence needed nursing care from others. This granted the person a sick role, which qualified him or her to receive support and care from those around them. Importantly, care was defined in focus group discussions with members of the larger Kibera community as tending to, or looking after, people who were physically not well enough to take care of themselves. HIV care is much more than biomedical. It includes emotional, social, economic and physical needs. Care activities involve nursing care services (bathing, help with going to the toilet, administering medicines, cooking, and feeding), providing food, performing household chores, visiting the sick (at home and in hospital), listening and accompanying the sick to hospital for clinic visits. PLHIV in the Kibera community, on the other hand, considered care to include the material support required to access food and

clinical care necessary, even in improved health. Emotional care was also considered critical by those I encountered at KNH, who described care as including both looking after someone (*kutunza*, or caring for) or nursing care, and being concerned or mindful of someone (*kujali*, or caring about) or those material and compassionate activities including communicating, visiting, and being available in times of need.

In defining HIV care for this thesis, three elements are considered: the practices of care, types of care, and resources of care. Care is thus defined as *all those actions and practices – nursing, clinical, advocacy, social, economic/material, spiritual, and psychological/emotional – and resources provided by others or the sick person themselves to not only enhance coping ability and well-being, but to make life meaningful in the bodily sense of being*. Care includes a wide range of mundane actions and practices, both hands on and from afar, related to nursing care, food, taking medicine, household chores, access to health care services and information, legal help, empathy, prayers, friendship, sense of belonging, sharing of experiences, providing and receiving advice, advocating for individual rights, reassuring, listening to and communicating, and material or financial support, while also taking into consideration autonomy and the self-respect of the individual. HIV care is done by family, friends, home based care (HBC) programmes, HIV support groups, post-test clubs, and occasionally the wider community, and increasingly the self

'Support' as a component of care

Although studies on care in illness rarely define 'support', care and support often overlap. Anthropological definitions recognize support as inherent in care-giving activities (Kyakuwa, 2009; Kamau, 2009; Bowie et al., 2006; Atchley & Barusch, 2004). Marianti (2002, p. 5) defines support as the 'assistance, help, and "backup" provided by others to cope with economic, social, psychological or emotional and practical problems, including nursing care'. Support can also include visiting, telephoning to learn how the person is faring, and encouraging social interactions (Bulmer, 1987), similar to the notion of 'caring about' as used by participants in the KNH support groups. The WHO's (2004) definition of support was limited to psychosocial ways of addressing the psychological and social problems of PLHIV, and their partners, families, and caregivers. Such ways include counselling and social support to help people deal with stressful situations such as stigma, adjusting to an HIV-positive diagnosis, and adhering to treatment.

In this study, HIV ‘support’ denoted different things to different actors. For donors and development partners, particularly PEPFAR, support meant mainly economic aid and the alleviation of emotional pain. According to PEPFAR representatives I interviewed, support included nutritional, physical, and psychosocial support. To the agencies that implement HIV treatment programmes, support was the assistance or help given in the form of encouragement to adopt the prescribed behaviours, such as accepting one’s HIV status and adopting behaviours associated with ‘living positively’ (such as safer sex, dietary recommendations, and treatment adherence). People in the Kibera and KNH support groups who were infected with HIV had varied definitions and meanings of support that were often shaped by socioeconomic status.

Support as ‘walking together’

Among KNH support group members, support could be psychological, moral, social, or informational. As members of the (lower) middle class, they tended to *msaada* as intertwined with poverty and inequality, and thus something with which they did not want to be associated. Instead, support meant encouraging or helping people to put into practice ‘living positively’ messages, which at KNH included the acceptance and ‘owning’ of one’s HIV positive status identity, adhering to treatment regimens, adopting positive attitudes and acceptable lifestyle behaviours (safe sex, disclosure, reduction of alcohol and substance abuse), confronting stigma, family planning, following dietary recommendations, keeping clinical appointments, monitoring CD4 cell (or T-cells) count, and participating in psychosocial support groups.

Empathetic phrases such as ‘*tuko pamoja*’ (we are in this together) and ‘*tumesimama na wewe*’ (we stand with you) were used to communicate support. *Tuko pamoja* was also used to refer to emotional compassion in the HIV journey. The expression was used when group members were emotionally expressive, including when sharing experiences of stigma, reporting a drop in CD4 count, expressing feelings of isolation, sharing life’s disappointments, and discussing the challenges of practicing safe sex or managing sexual dysfunctions and reproductive issues. Emotional support also extended beyond personal suffering to include social and family issues, such relatives’ weddings and the education of children. When new members joined the group, they were often distraught, and group members used the above expressions to encourage them and show empathy. Although

tumesimama na wewe could sometimes imply material and moral support, such statements were usually used in contexts of emotional support, and in defying contested prescriptive living positively messages such as disclosure, following dietary recommendations, and reproductive issues.

At the end of KNH support group sessions, it was common for members to briefly express their views about the session, including how they felt. Two phrases were often repeated: 'I feel supported' and 'I am empowered'. To this end, members expressed being satisfied with the assistance received, including advice, information, friendship or social and emotional support. In private however, a few peer mentors and group members expressed disappointment with the focus on psychological and informational support in this setting. Material support was perceived to be the 'real support'.

'Support' as *msaada*

Unlike the KNH concept of support, in Kibera the material aspects of care and support were dominant. Oosterhoff et al (2008) have stressed the importance of HIV funding in shaping HIV self-help groups. In Kiswahili, the term *msaada*, which literally means help, normally connotes a sense of inequality and obligation. Those who have are expected, when asked, to help those who do not have. In Kibera, '*msaada*' was used to mean material support for the needy, including foodstuffs, monetary assistance (for rent and tuition), and clothing. The words 'support' and '*msaada*' were used interchangeably, with support being used primarily in support group spaces and *msaada* in the wider community. Support and *msaada* were seen as tangible and immediate, and tied to both physical and psychological relief.

Within the Great Lang'ata women's group, the availability of *msaada* was used to make decisions about participation in support groups. Faced with stigma, poverty, (economic, physical, and social) incapacitation, and death, people participated in support groups not only as a gateway to life-saving drugs, as conditioned by Médecins sans Frontières (MSF) Belgium in Kibera, but also to life-saving food.

Support was also referred to as '*unga*', or 'flour' in English, and was used in the same way that 'daily bread' is used in English. Just as *unga* is a staple foodstuff in Kenya, so was food considered a staple of good care. After all, ARVs do not work in isolation: people also require good nutrition if they are to thrive. Good nutrition was not only widely recognized as

an important component in treating HIV effectively; some participants also refused to take ARVs if they did not have enough food (Prince, 2012; Kalofonos, 2010), believing that the medicines were too strong and would make them weaker, or that the medicines would not work properly without food.

When faced with the material realities of their everyday lives, I came to see that people living with HIV in Kibera were not simply victims of a ‘culture of dependency’, but rather consciously ‘played’ the aid game to access both *msaada* and opportunities, which they considered essential for survival. It should also be noted that I was not alone in feeling discomfort when confronted by the *msaada* culture in Kibera. Numerous researchers and NGO workers I met throughout my research quickly condemned support group participants who seemed to be mainly interested in material gains. For example, as the *msaada* framing of support grew in Kibera, MSF, which had first introduced support groups there, dropped the term all together and began referring to its support groups as ‘post-test clubs’ to make it clear that they were not offering material support.

‘Support’ as ‘my brother’s keeper’

Among MSM sex workers, care and support were intertwined with the biblical concept of being ‘my brother’s keeper’, which was used to refer to the sense of shared moral obligations they had to one another, and the expectation that they would watch over one another because they shared three intersecting identities: being HIV positive, being a sex worker, and being homosexual. The concept functions to organize care and support in this community shaping into human right activism. Among them, caring and supporting went beyond the types of nursing activities associated with HIV care and included providing shelter for one another when needed, listening to and communicating with one another, keeping each other company as friends, protecting one another from abusive clients, standing up collectively against harassment from police and homophobes, contributing to each other’s medical bills, encouraging one another to utilize HIV services and continue with medical treatments, and advising one another as they struggled with their shared and entwined identities as male sex workers living with or at high risk of contracting HIV and other sexually transmitted diseases without human rights. They also explicitly discussed ways they could link the specific challenges of male sex workers to the development and rights-based agendas of organizations

working with and on behalf of Lesbians, Gay, Bisexual and Transgender (LGBT) people, sex workers, and HIV positive people.

From support to support groups

Patient support groups for many conditions such as alcoholism, cancer, mental illness, drug abuse, ageing, and leprosy has been documented before HIV (Hilleras et al., 2001; Krause, 2001; Hough et al., 2003; Spiegel et al., 1981). Such groups are defined as groups of people or patients facing similar conditions or stressors who come together on a regular basis to share their problems or experiences and learn from each other about how to move through their situations. Usually, the groups are formed by people with stigmatized or chronic health conditions (Davidson, 1999). Often faced with incurable conditions, group members look for comfort or encouragement from each other (Rosenberg, 1984).

Patient support groups were based on the premise that the problems and the needs of members were not being met or could not be met by existing social institutions and health care systems (WHO, 2003a). Patients banded together to help each other address a common problem or shared concerns (Davidson et al., 1999). Meeting or being in touch with other patients can encourage the sharing of experiences and information, connectedness, confidence, solidarity, emotional well-being or happiness, and the formation of new social networks (Bowling, 1996; Farquhar, 1995). Those who have achieved some success help those who are struggling with similar experiences in a compassionate manner (Davidson et al., 1999; Helgeson & Gottlieb, 2000).

Learning new ways to handle challenges, cope with changes, and maintain new behaviours are all important aspects of the support group experience (Gottlieb, 2000; Martin et al., 2001; Montazeri, 2001). The groups may be facilitated by professionals or peers (Gabriel, 1996; Steinberg, 1997). Widely referred to as 'social support', this care and support from fellow patients enables them to share experiences in dealing with the same illness, and is vital in living and coping with incurable conditions (Rodgers, 1995; Atchley & Barusch, 2004; Bosworth & Schaie, 1997; Seeman et al., 1994; Van Buuren et al., 1992).

In many works on support groups for different conditions, the therapeutic effectiveness of these groups, including the improvement of quality of life and adoption of coping skills has been noted (Sivesind & Baile, 1997; Galanter, 1988). These groups also

have dilemmas (Fillieule & Duyvendak, 1999; Duyvendak & Nederland, 2007). Some other studies have shown the capacity of these groups in engaging in other in other activities other than the initial intent (Rabinow, 1999; Zinman, 1986; Zinman, Harp & Budd, 1987). The work of Toseland and Rivas (2005) shows that patient support groups have a tendency to change constantly (p. 91), and that they can unleash both powerful and harmful forces (p. 64).

In defining HIV support groups, the Treatment Action Campaign (TAC) of South Africa write:

in a support group people with the same problem find ways to cope with and defeat the problem. For example, people with cancer form support groups to help each other cope. People who have survived traumatic experiences like rape or other forms of abuse come together to discuss their problems and find coping strategies. With HIV, support groups have to go beyond psychological support and have to also focus on improving services. We also have to ensure our rights are respected. (Treatment Action Campaign [n.d.]

This definition is characteristic of TAC's activist nature. In their guidelines for establishing and operating successful support groups for people living with HIV, Catholic Relief Services (Fanelli & Moyo, 2008), an international development organization, defines a support group as 'a group of people who come together to talk about a challenge, experience, and/or role that they have in common without being judged, blamed, stigmatized, or isolated' (p.1).

The African Medical Research and Emergence Foundation (AMREF), an international NGO involved in the facilitation and strengthening of HIV support groups in Kenya, defines support groups as groups of individuals with a common need who come together to share experiences and support one another (2006). These groups, in the works of Cohen in Mundell (2006), are formed to offer care and support to people living and affected with HIV. Specifically, the groups are to provide a safe environment to share experiences, help with treatment, cope with stigma, deal with new challenges, advocacy, and to educate and create awareness in communities (Visser et al., 2005; De Barros et al., 2004)

In Kibera support groups were understood to be places where PLHIV met to seek or gain access to tangible support. For both PLHIV and ordinary people in Kibera support groups were synonymous with material benefits. This became apparent when funding began to decline and many support groups shifted their focus to income-generating activities. There was an attempt in Kibera to differentiate between support groups and post-test clubs even though some argued it was the same thing:

This is not a post-test club or treatment literacy. This is a support group. We do income-generating activities. In support groups we engage in bead and dress making, group savings and loans, and merry-go-rounds. (HAKI support group member)

At KNH, support groups were defined as a forum where PLHIV could meet to exchange life experiences and learn from each other about how to cope with HIV-related challenges:

Health providers may share what they have learnt from a book ... but in a support group we facilitate a forum where everyone shares their own experiences and challenges. You will find that a problem affecting one of the members, maybe one of the members has passed on ... so the patient with experience can share how they managed the problem and those going through it may learn from it. Secondly, PLHIVs are facing so many challenges with our family set-up, such as issues with spouses, children, parents, and community members. In support groups, we discuss these issues in depth so that members can understand how they can live positively.

(KNH support group peer mentor)

As mentioned above, the male sex workers' group was more than a support group: it was a space of friendship that utilized metaphors of kinship to frame care and support obligations based on principles of reciprocity and trust.

In this thesis, support groups are informal face-to-face or online assemblies of people with similar conditions or problems that provide possibilities for coping mechanisms. HIV support groups can be best understood as voluntary assemblages of people living with HIV who regularly meet face-to-face to share and address common concerns and problems in non-stigmatizing or intimidating environment; together they provide and receive care and support from each other, and may engage in various activities to chart their life course forward, often framed within a notion of empowerment. The groups are therefore a basic, local-level care and support unit that can be informal or formal, structured or spontaneous, closed or open, peer- or professional-led, and community- or health facility-based. HIV support groups are initiated by PLHIV, by health facilities, and by NGOs or CBOs providing HIV services (T. Nguyen, 2009; Oosterhoff, 2008; Oosterhoff et al. 2008; NACC, 2005; NACC, World Bank & UNAIDS, 2009; NASCOP, 2008a). The groups are spaces that are of interest to individuals, development partners, and public health interventions.

HIV support groups adopt different logics in responding to needs and interests of members. The great majority of HIV-related groups I came across were exclusively for people living with HIV, although there were caregiver and discordant couple groups that included HIV-negative people. In addition to 'support group', other common terms used for

social groups of PLHIV include, self-help groups, community-based organizations, buddy groups, care groups, professional groups, post-test clubs, and dating agencies. Most community-based groups in Nairobi also register as self-help groups or community-based organizations, and a few even as NGOs, usually because these registrations were required to apply for funding and process donations.

HIV and the rise of support groups

Remember, someday the AIDS crisis will be over. Remember that. And when that day has come and gone there will be people alive on this earth – gay people and straight people, men and women, black and white – who will hear that once there was a terrible disease, and that a brave group of people stood up and fought and in some cases died so others might live and be free. (Russo, 1988, p. 1)

This speech, entitled ‘Why We Fight’, was delivered at an ACT UP demonstration in Albany, New York, on 9 May 1988, and at the Department of Health and Human Services, in Washington, DC, on 10 October 1988 (AIDS Coalition to Unleash Power [ACT UP], 1988), by American activist Russo in the early years of the ACT UP movement when HIV and AIDS had no treatment. At a time when people with AIDS were dying, groups of people infected and affected by the disease were initiated in many places around the world as sites of political activism, community mobilization, and care and support. Over the past three decades, perhaps because of the huge numbers of people infected and the aggressive nature of the virus, HIV-related support groups, especially in Africa, have overshadowed other patient groups, organizations, and networks in number, activities, visibility, and locations. They have played a critical care and support role in community and public health responses to HIV and continue to dominate HIV interventions (Lyttleton, 2004; De Barros et al., 2004; Collins & Rau, 2000; Spirig, 1998; Epstein, 1996).

In the early years of the epidemic, support groups grew in response to the lack of treatment, the need to cope with feelings of desperation about inevitable death, and negative attitudes toward people with the disease. Those diagnosed with HIV were seen as dying, and governments around the world failed to protect the health of people with AIDS. HIV support groups first appeared in the United States in the early 1980s in gay communities, among people who mobilized each other as buddies, and later in the United Kingdom in health

facilities. The power of these groups lay in their psychosocial role, which later transitioned to radical activism and political action focused on human rights, financial resources, treatment research, and access to treatment (Jackson, 2002; Spirig, 1998; Epstein, 1996). The best known of these groups was ACT UP, or AIDS Coalition to Unleash Power, a social movement formed in 1987 in the United States and later in United Kingdom and France by gays and lesbians (Fillieule & Duyvendak, 1999).

ACT UP was structured through smaller affinity groups. The movement organized activism around the acceleration of HIV research, affordable treatment, and the enforcement of social values and human rights (Epstein, 1996). Activist campaigns included street demonstrations that received media coverage. The movement was overwhelmed by caring for people dying of AIDS-related illnesses in hospital, as noted by Vito Russo, 'in a lot of ways, AIDS activists are like those doctors out there – they're so busy putting out fires and taking care of people on respirators, that they don't have the time to take care of all the sick people' (<http://www.actupny.org/documents/whfight.html>). These groups, like ACT-UP France, were not asking for sympathy but focused on demanding for equal treatment (Fillieule & Duyvendak, 1999). ACT UP's powerful advocacy for the rights of people with AIDS and HIV resulted in the increased availability of HIV funding, biomedical advancements, affordable prices for ARVs, reduced stigma and discrimination through community awareness and education, and change in political will. Patient groups associated with HIV expanded into social movements in the West and beyond.

The global South was not left behind in this development, with home-grown or organic HIV support groups appearing in the late 1980s and early 1990s, some with influence from the North, while others spontaneously emerged. HIV-related patient groups were among the first therapeutic communities in Africa formed around shared health status. Iliffe (2006) writes about the 'Body Positives' group, which was formed in South Africa in 1987 by men who have sex with men. He also writes about the formation of Zambia's 'Positive and Living Squad' (PALS) around 1991 by Winstone Zulu, the first HIV-positive person to go public about his condition in Zambia. Other early groups were formed in Uganda, Senegal, and Burkina Faso. These groups had two distinct foci: first, psychosocial and informational support (helping people with AIDS live positively, with hope, less stress, and healthy practices) in the face of discrimination (Nakabugo et al., 2012; Jackson, 2002) and, later, gaining access to ARVs and influencing adherence to Antiretroviral Therapy (Nakabugo et

al., 2012; V.-K. Nguyen, 2010; V.-K. Nguyen et al., 2007; Jackson, 2002). More groups were reported in Malawi, Zambia, and Zambia in 2000s (Jackson, 2002).

Most HIV groups or associations formed in sub-Saharan Africa lacked a radical and confrontational approach, and therefore were not as powerful a political force as those in the global North (Iliffe, 2006; Jackson, 2000). In South Africa, however, in 1994, a number of groups joined together to form the National Association of People with AIDS (NAPWA). And in 1998, the South African Treatment Action Campaign (TAC), modeled on anti-apartheid political activism, became the first radical group on the continent, calling for HIV treatment for all and fighting against discrimination. With the increase in morbidity and mortality, and the arrival of HIV funding and technologies, support groups in the global South swiftly spread among affected communities, though mainly among low-income groups (Jackson, 2002), and, with the interest from development partners, they served as a platform for creating and strengthening civil society organizations.

Although some might argue that such collectives were introduced to Africa from the West, in Kenya home grown groups spontaneously emerged late 1980s before any contact with the outside world. In fact, Kenya's first contact with outside world on learning more about HIV support groups was Zambia. According to the oral histories I gathered from long-time survivors in Nairobi, it seems that home-grown groups were formed in Kenya in the late 1980s without any encouragement or funding from the outside world. High levels of stigma, imminent death due to lack of treatment, and ambivalent government response encouraged people to come together to provide moral support to one another and to share knowledge. Such social collectives can also be traced to the notion of *Harambee* (pulling resources together) introduced by Jomo Kenyatta, the first president of Kenya. Mutual savings groups were formed by cooperatives, clans, church and ethnic groups to fund a wide variety of social and welfare needs, including funerals and initiation groups. Prior to HIV, women, in particular, commonly set up merry-go-round groups to pull together resources. The financial element of such groups has surely shaped the formation and modelling of community-based HIV support groups in Kenya. For instance, the Kenya Network of Women with AIDS (KENWA) began as a welfare group where women with HIV and AIDS contributed money to help each other.

Various stakeholders committed significant resources to the expansion of support groups as a strategy to control HIV, create better treatment outcomes, mitigate the socioeconomic effects of HIV, deal with sexual needs of PLHIV, and assist their

reintegration into society. The content and practices of support groups, as well as people's motivation to participate in them vary substantially, not only between the global North and South, but also between countries, between different socioeconomic and demographic populations, and between community- and institution-based groups. Support groups are therefore dynamic and not static phenomenon. In Kenya HIV support groups have been a key resource for community-based education, outreach, care, and support. Despite the important contribution support groups have made to the HIV response in Kenya, very little research has been conducted on these groups. Johnson & Khanna (2004) have written about the important roles played by support group members in terms of care provision prior to and in the treatment era. As a key part of various interventions, HIV support group members were trained to provide home- and community-based care, and some earned allowances from NGOs and community-based organizations in exchange for providing information and nursing care to sick and dying patients at home (Johnson & Khanna, 2004). Others writing about support groups in Kenya have documented the important role they play in encouraging members to disclose their HIV status (Gillet & Parr, 2010; Hardon et al., 2013).

Given the widespread incorporation of support groups into HIV care, a better understanding of these groups is critical. We know little about the evolution and specificities of these groups in delivery of care and support for PLHIV. Less is known about the diversity, dynamism, and inequality of these groups given the wider issues that arise when they are expected to become both the providers and receivers of a wide range of activities. Even as sexuality has been brought into public domain in HIV era, there is a dearth of insights into the changing needs of PLHIV, particularly the sexual and reproductive needs of people with HIV, and how support groups meet or do not meet those needs. Furthermore, little is known about how the experiences of PLHIV have redefined care and support. What is still needed is a full picture of the evolution, diversity, dynamics, content, and happenings of support groups; and how support groups are related to the reconfiguration of care arrangements and the daily practices of living with HIV.

Social science and HIV support groups

Social science researchers have widely documented the positive – mainly psychological, social, economic and health – effects of HIV support groups on the lives of PLHIV (Heyer et

al., 2010; Liamputtong et al., 2009; Mello et al., 2009; Oosterhoff, 2008; Oosterhoff et al., 2008; T. Nguyen, 2009; Visser et al., 2005; Johnson & Khanna, 2004). The main psychological contributions of support groups are helping people to accept their HIV status, providing a safe and non-judgmental environment to share experiences, and promoting change in mental outlook (Kyakuwa, 2011; Heyer et al., 2010; T. Nguyen, 2009; Visser et al., 2005; Johnson, 2004; Tsasis, 2000; Kalichman et al., 1996). Research shows that accepting one's HIV-positive diagnosis is an important first step in overcoming anger, denial, and depression, and can eventually contribute to greater self-acceptance, the building of self-confidence, and adopting strategies for coping with HIV (Heyer et al., 2010; Liamputtong et al., 2009; Visser et al., 2005; Kalichman et al., 2006; T. Nguyen et al., 2009; T. Nguyen, 2009; Van Devanter, 2000; Jackson, 2002). Studies have also shown participation increases social contact and results in building relationships that help to generate a new sense of belonging (Heyer et al., 2010; Liamputtong et al., 2009; T. Nguyen et al., 2009; Visser et al., 2005; Jackson, 2002; Van Devanter, 2000; Kalichman et al., 1996). Support groups have been credited as a platform for social transformations that challenge stigma, for creating and redefining social relations and connectedness, and for giving meaning to the lives of people with HIV (Tsasis, 2000).

These groups have been noted to be an important source of information; members benefit from information on nutrition, HIV, treatment, behaviours, and available health care services among other things (Heyer et al., 2010; T. Nguyen et al., 2009). The information gained helps patients participate in their own care and decision-making regarding their condition (Helman, 2000). This information helps people to cope with HIV, encouraging them to invest in self-care, to focus on treatment adherence and nutrition, to access HIV services, and prevent new HIV infections (Heyer, 2010; T. Nguyen, 2009; Helman, 2000). In a study in Vietnam, T. Nguyen and colleagues (2009) argue that as HIV-positive women gain information about available services and engage in a self-esteem-building support group, they also gain confidence to access health care, including HIV services.

The economic and material benefits of support groups have also been widely documented. HIV has opened doors to funding and job opportunities both to organizations and to individuals. Support groups may serve as avenues for channelling assistance in the form of direct funds, income-generation activities, and job opportunities (Visser et al., 2005; Heyer et al., 2010; Kyakuwa, 2009; Visser & Mundell, 2008; Oosterhoff, 2008; Oosterhoff et al., 2008; T. Nguyen et al., 2009; Jackson, 2002; World Bank, 2000).

There has been a great deal of social science and even anthropological research on HIV and social support and it would be impossible to review all of that literature here. Most significant to my thinking have been studies by Oosterhoff and associates (2008), Rhine (2009), Marsland (2012), Kyakuwa (2011), and Le Marcis (2012).

Oosterhoff and associates (2008) writing about PMTCT self-help groups in Vietnam reveals that HIV-positive women in self-help groups accessed income-generating activities' funding and job opportunities, in particular peer-counselling opportunities. Such opportunities, suggests Oosterhoff and associates, were only available to PLHIV, and had a positive effect on the health, social-cultural milieu, legal-political empowerment, as well as self-esteem of the women. However, she writes that such self-help groups last only as long as the funding. The study therefore provokes an exploration into the relationship between support groups and HIV funding or development projects, and the resilience of these groups when groups have outlived funding.

Rhine extensively describes how HIV-positive women in northern Nigeria appropriated support groups to facilitate their marriage arrangements. She concludes: 'The support group space, intended by interventions for social and health wellbeing, and cultivating self-responsible and economically responsible patients, was used by women to respond to their (marriage and intimate relationship) needs and desires' (Rhine, 2009, p. 370). PLHIV continually re-fashion support groups to better meet their needs and desires. Where support groups fall short of responding to such needs and desires, members drop out or hop from group to group in search of fulfilment. For instance, the men's sex therapy support group in KNH was carved out of the mixed adult support group to respond to male sexual issues. Similarly, the male sex workers in the Freedom Corner support group members first started coming together to address needs not covered by existing HIV interventions. The HIV interventions created a platform for the men in these two groups to re-make support groups that would respond to their emergent needs.

Kyakuwa (2011) extensively studied care provided by HIV-positive care workers in Uganda. In her analysis, she writes about how HIV-positive health care workers were worried about the damage to their bodies by ARVs; undesirable side effects would negatively affect their delivery of services to their HIV-positive patients (Kyakuwa, 2011, p. 147). This, writes Kyakuwa, threatens their confidence. In a remarkable description, Kyakuwa has shown how the support group space provides the HIV health care workers a forum to share about their experiences with side effects and it helps them to go the extra mile in offering services to

their HIV positive clients, thus improving their productivity.

The limitations of support groups, however, do not feature prominently in the literature. Although research shows that HIV support groups play an important role in coping, such research may not address important individual needs or the specific happenings of these groups. Recent studies on support groups, by Marsland (2012), Prince (2013), and La Marcis (2013) who work in Tanzania, Kenya, and South Africa respectively, uncovered the limitations of these groups in meeting the daily essential needs of members. These studies suggest the need for more in-depth research and analysis of how individuals relate to support groups, what actually happens or does not happen in support groups, and whether they benefit members' lives or not while recognizing the individual's multiple needs and positions.

Social relations and HIV: a theoretical perspective

A well-known theoretical concept relating to collective social support for HIV and AIDS is that of 'therapeutic citizenship', proposed by Vinh-Kim Nguyen (2010) to account for the ways that local forms of HIV activism and support are directly and indirectly informed by both state and global policies, practices, and human actors. In his work in Burkina Faso and Cote d'Ivoire in the late 1990s, Nguyen observed the relationship between the emergence and development of community-level HIV support groups around the quest for life saving drugs from the global North that were extremely scarce at the time. Although his research took place prior to widespread treatment availability, it remains relevant today as a reminder to attend to the relationship between the development of new social relations and expectations of care and support. In this study, it led me to ask: How significant are expected benefits to the creation of and participation in support groups to PLHIV?

Another important theoretical concept for this study is that of 'biosociality', first coined by Paul Rabinow (1992), particularly in regards to the relations formed around HIV seropositivity. As a starting point, this framework allows me to explore how HIV-positive status (a biological condition) led to formation and maintenance of new social relations leading to a new social institution: HIV support groups. In *French DNA* (1999), Rabinow explores and analyses how biotechnology became a force in shaping social relations and collective identities among people sharing a biological marker, meaning a disease, health risk, or genetic predisposition for a disease. He demonstrates the importance of imagined

future stakes in encouraging people to come together to exchange new knowledge and mobilize resources. Rabinow's main interest is demonstrating the potential ability of biotechnology to bring about new social relations, an idea that has been further advanced by Lock (2002) and Novas (2006) among others. Whereas Lock examines the significance of technological advancements around human organ transplants to social relations, Novas examines the emergence of patient organizations in biomedical research.

Although HIV-positive status as a basis for social relations has been challenged, my research demonstrates that it remains an important if not always primary basis for the creation of HIV support in Nairobi. The question whether there are other factors more important than HIV has been argued by Marsland (2012). In her study of HIV support groups in Tanzania, Marsland argues that PLHIV were more likely to forge collectives based on pre-existing relations rather than solely on shared biomedical status. Although I agree with her that pre-existing social relations can play an important role in motivating some support groups to come together, I argue that a shared biological status remains fundamental in facilitating HIV support group formation.

I theorize HIV support groups in three dimensions. The first dimension focuses on HIV testing as a biotechnology that facilitates social relations based on shared identity, one in which a biological marker intersects with political, social, and political challenges. In the early days of the disease, PLHIV grappled with HIV-positive identity and with the failure of government and society to protect their health. In the treatment and post-treatment eras, PLHIV are now concerned with accepting HIV status, figuring out a new identity, returning to normal life, facing stigma, and leading meaningful lives on treatment. The social collective of the support group provides a context for people with a shared biological marker to come together to address these concerns, exchange information, and mobilize resources.

These social collectives are thought to be valuable for people living with HIV for two reasons: they orient people toward the future and they compensate for a lack of familial support. The first reason hinges on hope; as noted by Novas (2006, p. 291) the hope that is cultivated in patient groups is 'both individual and collective: it ties together personal biographies, collective hopes for a better future, and broader social, economic, and political processes'. Novas further explains that to 'live in hope means to take an active stance towards the future'. PLHIV do not join support groups just to show they are infected, they do so because they need care and support in various ways. They are driven to take action and perform a range of activities for themselves, their peers, and their communities. They

empower people with HIV to work out complex psychological feelings and experiences; make physical, economic, and social improvements; and reorder their life courses (Rhine 2009; Lennon-Dearing, 2008).

The second dimension in which I theorize support groups focuses on other HIV-related technologies that lead to creating, redefining, and shaping social relations among PLHIV. These technologies include ARVs and infant feeding programs that prevent mother-to-child transmission of HIV. These technologies help to facilitate the increasing biomedicalization of HIV (V.-K. Nguyen et al., 2010). HIV global policies, donors, and biomedical experts have played a fundamental role in influencing or determining social relations of people living with HIV and what support groups should do. Support groups are viewed as cost-effective spaces to produce optimal treatment adherence and increase the success of HIV prevention programs via collective social enforcement.

Prior to the introduction of ARVs, debates about the adherence capabilities of patients living in low-resource settings circulated widely (Popp & Fisher, 2002). When HIV treatment was finally to be made widely available in such settings, adherence was a primary worry of donors and international public health experts. Support groups were understood to be ideal spaces to encourage ideal patient behaviour. Along with treatment expansion, support groups proliferated, especially in health facilities, and existing support groups were re-fashioned to serve as spaces where people could simultaneously learn about HIV and HIV treatment and learn to take responsibility for their own self-care, treatment adherence, and prevention (Simbaya & Moyer, 2013). Early treatment providers, such as MSF Belgium, required people to attend treatment literacy trainings and attend group meetings to become eligible for antiretroviral treatments. Support groups became an essential health care domain within an unequal but highly globalized world (Farmer, 1999).

The third dimension in which I theorize HIV support groups is the colliding of several factors such as economic needs, sexuality issues, HIV-positive status, and biomedical interventions. Whilst it is true that HIV-positive status is fundamental in these social relations, material needs, economic circumstances, and sexual factors also play a major role in determining the existence of these groups. Material concerns and shared sexual identities and challenges significantly motivate PLHIV to join together to address specific needs. One of the hallmarks of a successful support group (though it can also contribute to splintering) is its ability to facilitate members to organize and address their specific interests or needs. Individuals sometimes join existing groups because they appeal to their interests, but also,

and just as importantly, they utilize support group spaces to craft their identities to gain specific benefits associated with those groups.

HIV-positive status alone does produce social relations: there has to be ‘real’ support to motivate people’s participation in support groups. Material needs and other desires are pursued; in this sense, biosociality alludes to intersections between HIV funding and HIV status. Although financing is often critical for the formation and survival of support groups (Oosterhoff et al., 2008; T. Nguyen, et al. 2009), the lifespan of groups is not entirely dependent on donor funding. In the absence of donor funding, some groups venture into other income-generating activities.

In addition to material concerns, other shared biological or social identities also brought specific people together. In my research, the most salient identity issues were connected to sexuality and gender, including sexual orientation and sexual dysfunction, as well as class and job status. For example, being a sex worker was an important intersecting identity that brought MSM together at Freedom Corner. For those in the men’s sex therapy group their concerns about sexual dysfunction were intimately entwined with heteronormative masculinities.

Being HIV positive and being targeted by HIV interventions combine with existing and emerging social identities to shape new biosocial identities and new biosocial collectives. These are both specific and diverse, and also depend on time and geography. In the remaining chapters, I historicize HIV support groups and present case studies of the various support groups I studied in-depth to illustrate both the specificity and diversity of HIV support groups in Nairobi.

CHAPTER 3

HIV SUPPORT GROUPS IN HISTORICAL PERSPECTIVE

Introduction

I had just completed a support group session with the Tumaini Support Group in Kibera when Jemima, the group leader, asked to speak to me in private. We walked out as we talked. She led me through a narrow and muddy pathway that led to her house. As we walked, she let her heart out, telling me about her illness and life's challenges. It was in January 2012. She had been bleeding for three days now, a condition she suspected was being triggered by stress.

When Jemima, a mother of seven, was found to be HIV positive in 1987, she was thrown out of her home by her husband; he died two years later. She went on to remarry a HIV-positive man in 2011. She lives with him, her two adult sons (aged 25 and 27) and a seven-year-old grandson. Despite her HIV status and joblessness, she is the breadwinner for her family. Her two sons were jobless and her husband, who worked on a casual basis as a watchman, was only paid on the days he worked. For a long time, he had been bedridden and had not gone to work. As such, he had no income.

I listened to Jemima as she lamented her abject poverty. She seemed to have ambitious plans to improve her living standards but she decried the absence of HIV funding that she had hoped would make a difference. Many opportunities had come and gone. Over the years, she had moved from one group to another hoping to get funding. But she was not successful. In 2004 she formed her own support group with the hopes of gaining access to and controlling HIV funding. There had been some opportunities with that group, but those too had slipped away. Her support group had been sub-contracted by an NGO to offer home-based-care services in exchange for allowances. Three months prior to my study, however, the sub-contract with the NGO had expired, rendering Jemima and her fellow group members jobless.

Many of the group's members left and sought other avenues of livelihood. Jemima was also involved in table-banking activities (see Chapter Two) with the remaining members of her support group, but that was unstable: some members could not raise the agreed amount of money, and others were busy with their own activities elsewhere. Some members had even taken loans and failed to repay. This resulted in internal conflicts, accusations and counteraccusations, disagreements, and even fights during sessions. Jemima also complained that she had shared her life experience on various radio stations but no one came to her aid. The case of Jemima's group was not

entirely unusual, and many support groups in Kenya were facing a similar fate.

Over the last three decades HIV support groups have been at the centre of HIV interventions in the lives of PLHIV. In my conversations with groups of people living with HIV, I heard passionate reflections on the evolution of support groups, their achievements, and their challenges that were not documented. To better understand the contribution these groups have made to the Kenyan HIV response, in this chapter and the next one, I examine support groups in historical perspective.

Through an examination of the shifts in support group practices and domains, which occurred in response to shifts in the framing and the responses to HIV and AIDS by state and global actors, I want to highlight the evolution, dynamics, diversity, and specificities of HIV support groups in Kenya. In looking at such a phenomenon, emerging social relations, and historical perspectives, I am spurred to ask: how did these groups emerge? What was at stake? How did PLHIV relate to and participate in support groups? In what ways have these groups become instruments for care and support for PLHIV? How have the functions and nature of support groups changed over time?

In this chapter, therefore, I focus on the pre-HIV treatment era, from the late 1980s to 2002, when support groups emerged sporadically and often organically, mostly at the community level. I explore the contribution of internal and external factors in the evolution of support groups. I begin by tracing Kenya's lukewarm early response to HIV and AIDS together and the social circumstances that resulted in the emergence of support groups in Kenya. I then discuss the ways that HIV funding shaped and intersected with the objectives of support groups, with a focus on the socioeconomic status of group members. To outline the history of support groups in Kenya, I have relied on media reports and the accounts of key informants who were among the first people to participate in formation of support groups. While media reports were helpful, they emphasized sensational moments of HIV such as stigma, deaths and money/funding. Therefore, I also interviewed other people who were key players in HIV support groups in the early days of HIV.

The failed state and societal responsibility

The first two decades of HIV in Kenya were characterized by ambivalence in the government's response (Okuro, 2009) and stigma (Grinstead et al., 2001). Funding was limited, and myths and misconceptions heightened stigma, and discrimination, which also

discouraged people from disclosing that they had HIV or AIDS. The state failed not only in the protection and maintaining of the health but also in promoting the wellbeing of its citizens.

In the 1980s and 1990s, Kenya's economy was at a low point and AIDS was met with virtual silence in the political realm (Okuro, 2009). In 1985, the Kenyan government established a National AIDS Committee that, according to Dr Cherutich, a former Prevention Manager at NASCOP, did not do much due to poor funding, and political commitment. In 1987, the National AIDS and STI Coordinating Programme (NASCOP) was formed to spearhead the fight, but they had limited resources and also were not able to accomplish much. At that time, the government was experiencing political and economic turbulence, and massive corruption had led international development partners to withhold funds (Rajab, 1997).

Although health was one of the state's three development pillars at Kenya's independence, public acknowledgment of the devastating effects of AIDS in the country was suppressed. A 1991 newspaper article entitled 'AIDS, a Disease for Immoral Society' condemned President Moi's government for failing to acknowledge the seriousness of HIV/AIDS and accused the state of being 'immoral to the extreme' (*Daily Nation*, 1 December 1991). Meanwhile, in neighbouring Uganda, the state was leading an all-out war on HIV (*Daily Nation*, 15 May 1990). Uganda's government quickly took measures to address HIV, establishing a National Committee for the Prevention and Control of AIDS that later evolved in 1986 into the National Control Programme (Kinsman, 2010). By 1990, 20 'post-test clubs' involving people who had been tested for HIV, both people who were HIV positive and HIV negative, were running in Uganda.

There was a general lack of HIV and AIDS information in Kenya at the time, which exacerbated fears of infection and the moralization of HIV transmission, leading to stigma and anxiety among the general public. The consequence was a societal failure to provide care and support to people with HIV and AIDS in the 1980s and 1990s (Spronk, 2014; Geissler & Prince, 2007). The social disorder that resulted was characterized by high levels of AIDS-related stigma and the increased isolation of people with AIDS and HIV, who were treated with hostility or shunned by their families, communities, workplaces, health facilities, and religious organizations (Grinstead et al., 2001; Geissler & Prince, 2007).

The media – which was the main source of information about HIV at the time (National Council for Population and Development (NCPD) & Central Bureau of Statistics

(CBS), 1998) – may have caused more harm than good. For instance, in January 1985, the newspaper *The Standard* sensationally reported on the ‘Killer sex disease in Kenya’ (15 January), ‘Horror sex diseases in Kakamega’ (18 January), and ‘Blood test for sex disease’ (January 19). In the story on ‘horror sex disease’ that appeared in *The Standard* on 18 January 1985, it was disclosed that four AIDS cases had been reported at the Kakamega Provincial General Hospital. According to the newspaper, the killer disease that first appeared in 1981 in the United States among homosexuals had reached epidemic proportions and was spreading to other parts of the world. The report noted the disease mainly affected homosexuals, but the reasons for this were still a mystery in Kenya; it further asserted that the disease could be transmitted to heterosexual people through kissing and blood transfusions. The following day, 19 January 1985, *The Standard* had another story titled ‘Blood test for sex disease’. HIV/AIDS was not a problem in Kenya. Apparently, all blood was to be tested for HIV as a way of preventing AIDS spreading through blood transfusion. Reporting about the exercise, Dr Kaviti, the director of National Public Health Laboratory Services, observed ‘We are not scared of AIDS because there are no cases reported but now that people are mentioning it so much we have to be scared-These days we have to take precautions because you can be in New York one day and in Nairobi the next’.

A few months later, 15 and 16 March, *The Standard* headlines reported two other AIDS cases: ‘Mystery AIDS killer in Kenya’ and ‘AIDS victim found dead’ respectively. These last two cases report in Nairobi correlated with those reported in Kakamega Hospital, but the medical authorities refuted this claim. There were glaring signs of a lack of proper information. Claims and counterclaims created an information vacuum as the medical practitioners seemed to fail the public. Public awareness through the broadcast media served to reinforce the deadliness and infectiousness of the disease. There were chilling messages such as ‘AIDS kills’, but these did not provide information on caring and supporting those with AIDS, but rather portrayed people with AIDS as those to be avoided at all costs. In an article titled, ‘AIDS is uncommon’, *The Standard* reported that Dr Ogondo, who was then the western provincial medical officer speaking at a meeting organized by the western division of the Kenya Medical Association (KMA), noted that AIDS was still uncommon and asked the media not to cause undue panic with statements not authenticated with statistics (16 March 1986). The 1989 first comprehensive five-year Medium Term Plan and 1991 Second Medium Term Plan by the government of Kenya reveal ambivalent HIV response.

However, the media continued to provide any information on HIV and AIDS to the

public. Most of it was frightening rather than informative or educative. On 19 March 1993, a picture of an emaciated AIDS patient was included in the *Daily Nation*. Mr Joe Muriuki, the first person infected with HIV to come out in the media in Kenya, recalled that in the early days chilling messages such as ‘AIDS is deadly’ were broadcast on the radio while posters in public places showed emaciated people dying of AIDS. These reports, he claims, instead of creating awareness and educating people, frightened those who were infected in addition to raising anxiety, fear, and stigma among the general public.

The problem with HIV was the mode of transmission (sexual), its ‘death-sentence-nature’, virulent infectiousness, and its slow progression to death, what Sontag (1990) referred to as a catastrophic slow death. In an information vacuum, HIV/AIDS was seen as a deadly infectious disease and a justifiable punishment for sexual sins or immorality (Geissler & Prince, 2007). It was a time of anxiety, anger, powerlessness, sadness, hopelessness, and frustrations for the infected and affected. Treating people living with AIDS with fear and suspicion intensified their helplessness, hopelessness, and depression (*Daily Nation*, 25 May 1990).

The infectious and aggressive nature of HIV and high mortality escalated stigma towards the infected and, sometimes, their families. People with HIV/AIDS were treated with hostility within families, communities, workplaces, and health facilities (Grinstead et al., 2001). Generally, the tone towards HIV/AIDS patients was accusatory. They were blamed for being responsible for an infection they could have prevented (Geissler & Prince, 2007). According to Muriuki, ‘Those who were symptomatic were feared, ridiculed, scorned, isolated, rejected, had their morality questioned, and were discriminated against’. Another newspaper article by Argwings Odera, ‘Being scared to death to be one of them’, reported that ‘People with AIDS are condemned, labelled, ridiculed, isolated, and abandoned, and those who died [are] buried in black polythene wrappers like second-class citizens’ (*Daily Nation*, 25 May 1990).

The persistent linking of HIV with sex and with immorality – in the form of prostitution and promiscuity – increased stigma and inflicted damage on the social fabric, as was found by Dilger (2008) in Tanzania. People with HIV and AIDS were seen to be responsible for their own misfortunes. They were considered not only infectiously dangerous but also socially dangerous other. Branded by some religious leaders as ‘sinners’, HIV/AIDS was considered a punishment inflicted by God for sexual promiscuity (Geissler & Prince, 2007). This resulted in denial, withdrawal, and social phobia among those infected. Women

whose husbands succumbed to AIDS were accused of having 'killed' them and were disinherited or chased away (Parker & Angleton, 2003). People who tested HIV positive and those who had developed AIDS were suffocated with negative feelings. 'We felt isolated, hopeless, stigmatized, but did not know how to vent our feelings', observed Muriuki.

Furthermore, employment and social relations of people with HIV and AIDS were severed. Businesses, spouses, parents, friends, relatives, money, and jobs were lost. Those who worked in private companies and government organizations became casualties of sackings and retrenchments. Vincent, for example, narrated that he was retrenched after suffering bouts of opportunistic infections. He recalls: 'At 32 years old I was relatively young. People who were above 55 years were the ones supposed to be retrenched first but I became the first to be shown the door because of my health, yet I was prescribed for AZT which was very expensive'.

Emergence of the Know AIDS Society (KAS) in Nairobi

It is within this context that a few people with HIV and AIDS began looking for contact with each other for companionate support and to take up the responsibility of being their brother's keeper. One of two surviving members of the group's original eight founders, Joe Muriuki, told me:

Those of us who experienced stigmatization felt that just as birds of the same feather flock together, people with HIV had to come together. The best way to get support was a place where they could come together to de-stigmatize HIV/AIDS, know they were not alone, help build their self-esteem, and feel they were human beings.

Another key informant, who was a board member for The Association for People with AIDS in Kenya (TAPWAK), related what it was like when his close friend Mr Lenya was tested:

When one of the founding members Mr Lenya tested positive for HIV, he came to me. He cried and told me, 'I am HIV positive'. Apart from his wife, I was the second person he told about his status. Those days it was very scary. ... Counselling services were not there and Joe Muriuki had gone public so I told him to look for Muriuki. I think he got counselling from Muriuki.

Mr Ragi, the director of KANCO, and a TAPWAK staff member, concurred that at the time stigma was very high: 'People who were HIV positive did not know how to cope with stigma, which was very high that time. It was, therefore, helpful for them to come together and share personal experiences'. It was in this spirit that a buddy group of people with HIV and AIDS emerged with the aim of sharing experiences, HIV/AIDS information, compassion, and propelling hope.

They first had to find each other. Joe Muriuki recalls:

I was an accountant at Nairobi City Council. A friend of mine who knew about my HIV positive status linked me to the late Mr Lenya who was also HIV positive. Apparently, Lenya and I were working in the same council but didn't know each other. So when someone who had known about me got to know of Lenya's status they referred him to me, and we got more people coming to us. ... Soon there were eight of us. I would say we found each other by accident because of the stigma and that is how we eventually started a group. ... They call them in London 'buddy groups', like friendship of people who were experiencing a severe sickness which was stigmatized and they needed the companionship of each other – so we started like that. These were people facing a severe sickness and were so stigmatized that they needed to encourage each other. So we were helping each other to cope, we supported each other, and it was a way of finding a place where we could be comfortable, feel free to talk about our condition without being judged and stigmatized. Basically that was what buddy groups²⁰ were about.

Onyango, another surviving member of the original group, notes:

People with HIV and AIDS cared for others with a similar condition. They wanted to protect those who were on their own. Even [their] families and relatives had rejected them; they were shunned, isolated, and abandoned. They were concerned at how people living with AIDS were being mishandled at home. This group provided a liberating experience. It was a way of finding a place where we could feel comfortable, feel free and talk about our condition without being judged and stigmatized. This was the first group of PLHIV.

Even though they did not identify themselves as a HIV support group, these key informants traced the emergence of HIV support groups to their 'buddy group', whose members included

²⁰ The homegrown groups that emerged did not use the term 'support group'. Some were called 'buddy groups' and others 'welfare groups'. According to Mr Muriuki, the terminology 'support group' came much later. To some people it was from Uganda while to others it came with MSF Belgium from South Africa to Mbagathi and Kibera.

Joe Muriuki, Lydia Wangeci, Tom Guda, Elizabeth Wairuri, Domitira Ndege, Azaria Omondi, Josphat Mutuku, Onyango, and Rawland Lenya. The first HIV support group in Kenya, KAS, according to the majority of my key informants, is linked to this organic buddy group.

Emergence of HIV support groups in Kibera

By the late 1980s, HIV/AIDS had become apparent, threatening the traditional systems of social support in Kibera. I discovered another organic HIV support group that emerged in Kibera slightly earlier than the buddy group. This group was an initiative of women living with HIV/AIDS but was led by a professional nurse who was HIV negative.

As noted above, Jemima tested HIV positive in 1986 and was consequently chased away by her husband (now deceased). ‘I did not believe the positive results, thus I kept taking more tests hoping I would test negative. The nurse realized I was in denial and told me to join a support group. But at that time, there was no such group in Kibera’, says Jemima. She later found five other women in a similar predicament who had sought health services from African Inland Church’s clinic situated near Kibera’s law court. Jemima recalled:

Because it was a clinic that used to test HIV, women who tested positive would meet there and share experiences. We talked about what was going on in our lives, especially those of us who had been put out of their houses together with their children. I then suggested to the nurse to start a support group for us.

In 1989, the nurse formed and facilitated a group for them, which met every day to share the challenges they faced within their families and community, and to support each other emotionally. The nurse soon left the health facility and the group was taken over by another nurse who was also a church minister. This nurse later lost her job but went on to start a small clinic in Kibera’s Kisumu Ndogo area (a Luo-dominant village in Kibera) and invited the women for group sessions. They also began a welfare fund.

The nurse explained:

These women came together not because of age, profession, or ethnicity but because of their HIV status. They shared what they were going through, how they were coping, and the kind of treatment they were receiving for opportunistic infections. They were doing things together as people infected with HIV. ... Then they decided to start a welfare fund to which they each contributed KES 10 [1 euro cent] per day to support those with economic problems, but it was

difficult because, little as it looked, some could not manage to raise such money. Others had lost hope and did not see why they should live. They would rather die early than suffer as they wait for death.

The nurse continued:

We have come from very humble beginnings. I never thought about this group becoming the Kibera Community Self-Help Group [KICOSHEP]; leave alone an HIV support group. Since I started a small, low-cost medical clinic at Kisumu Ndogo, Kibera, I invited the women to meet at the clinic and share their experiences, especially how they were coping. Many of them had social and financial challenges. I would link them up with support, mainly food. I used to visit people with AIDS who did not make it to the clinic. I was the key person in there: I had knowledge to talk with the government and I had knowledge to refer them for other services. Other people in Kibera heard about the group and joined, but they were mostly single mothers. They reached 27 women. Then we started a daily contribution of 10 shillings to help those who were having problems. Then we decided to call it self-help group, like a welfare group, in 1990. It was first a group. Progressively, it grew to become KICOSHEP. Eventually, 10 support groups were formed in different villages of Kibera. We got funding. As an NGO with donor support, we pioneered in offering a community VCT [voluntary counselling and testing programme], as well as a home-based care programme, and later orphans and youth programmes in Nairobi. As we changed to run programs we trained women to form and run their own groups. Some left to join other groups where they were offered peer education jobs.

Emergence of HIV support groups in upper and middle class

Save for Onyango who was once in the middle/upper-class support group, the absence of people from the middle and upper classes in the development of support group was noted with concern. Ragi says:

We know some people who passed on in a very bad way because of stigma. Some were doctors, nurses, and politicians. Some could not disclose to their colleagues. Support groups for the middle and upper classes have never been there in this country. They have not picked up at all. For instance, we had members of Parliament who were infected but never came out. They go for consultations behind the scenes.

According to the director of KICOSHEP, support groups were seen as places for poor people. In the absence of the elites, moguls were from the lower-middle and low-income strata. They came to represent all the people with HIV and AIDS, including the middle- and upper-income people who preferred privacy for fear of affecting their social status or jobs. A TAPWAK board member recalled:

It was very difficult to start a support group for high-profile individuals or have them join support groups. They talked about stigmatization by their colleagues and would call to ask our staff to get them drugs and supplements, and when they came on their own they stayed in their cars... they did not want to be seen. One who worked at Housing Finance had medical insurance coverage but preferred to buy drugs over the counter – which he did by calling one of the staff to pick them up for him. They did not want to join the support groups, yet would have learnt how to use the medicines there as private doctors do not have time to teach them. Some people from my workplace who knew I was a board member and a volunteer at TAPWAK used to send me for supplements but would never come to the TAPWAK premises because of stigma.

However, there was a continued effort to make people come out and rise above stigma, which was done through constant outreach and meetings. A TAPWAK staff explained:

After outreach to banks like Barclays and institutions like the Kenya Bureau of Standards and National Housing Corporation, we were shocked at the number of phone calls we received from infected people working in those institutions. They said they feared coming out because they were not sure of what would happen to them after disclosure. They were unwilling to join support groups... they did not want to be known even by others who were HIV positive. Though they had HIV, they did not wish to be associated with anything to do with HIV/AIDS, be it hospital or someone who was HIV positive.

During an interview with Onyango, I learned that a support group of middle-upper-class people emerged during the pre-treatment era in Kenya, but remained invisible. Onyango was a member of the group; he explained that during the pre-treatment era, the HIV treatment that came through a few private health facilities was very expensive in Kenya. Some middle- and upper-income people with means who could afford the expensive ARVs formed a support group known as Soul-to-Soul. They met in Lavington, an upmarket area of Nairobi. A doctor who practiced at the MP Shah Hospital (a middle-class, private, for-profit hospital) facilitated the group. The main concerns of the group were access to and sustainability of treatment, loss of property, and management of relationships. The group operated discreetly and coming out in public for this group was a no-no. Onyango said:

In the early years when treatment was scarce and expensive, it was a desperate time. The middle/upper class would sell their properties to find something that would bring hope in their lives. It was quite devastating because you sell your property, but no change. Others were conned, many of them lost jobs, and some gave away their property in frustration that they were dying soon. However, they tended to look down upon people who were not from their background yet they did not have courage to come out and advocate for PLHIV issues let alone their own issues. They relied on other PLHIV from lower levels to advocate for their issues. I do not blame those in the middle/upper class because being open about your HIV-positive status is an individual choice. But there are times when we want such people to open up to influence policy at higher levels. I know there are MPs who are HIV positive. But why didn't they come out to support the HIV fund that we wanted the government to initiate? Onyango seemed to suggest that if elites or middle-upper class PLWA joined support groups, it would have hastened government response, and perhaps, decreased stigma. However, based on his narrative, the elites and affluent people with AIDS did not have common concerns with low-income PLWA.

From victims to HIV moguls: inclusions, exclusions, and diversification

Mr Ragi who, a staff member at the Kenya Red Cross HIV/AIDS office (and later started the Kenya AIDS NGO Consortium where he was the director at the time of our interview) explained how by the mid-1980s, civil society began to show some response to HIV. Religious institutions, United Nations agencies, private charitable organizations, and NGOs made attempts to address HIV in Kenya. Most notable were the Kenya Red Cross, Christian Health Association, Action Aid, African Medical Relief and Emergency Foundation (AMREF), and Health Africa. In 1988, he explained, these organizations agreed that the Kenya Red Cross would set up an HIV/AIDS information office in Nairobi to create awareness and provide vital information. At that time, most people relied on HIV information from the media, which was often sensationalized.

In 1989, supported by Norwegian Red Cross and later Norwegian Church Aid, an international organization, the Kenya Red Cross HIV/AIDS opened an office in Nairobi. The office distributed HIV/AIDS newsletters from AIDS Watch UK and produced a series of 'Know about AIDS' pamphlets that provided information on HIV prevention. These

pamphlets were occasionally inserted in Kenyan newspapers to educate the public about AIDS. This office also partnered with the American Red Cross to provide information about HIV/AIDS transmission modes.

Mr Ragi noted that through the Know AIDS pamphlet and by word of mouth, Mr Muriuki's buddy group got to hear about the Kenya Red Cross HIV/AIDS office and approached them for information and individual counselling. However, the Kenya Red Cross HIV/AIDS office did not have counselling capacity. Therefore, they published a list of psychologists in a local newspaper from whom people with AIDS could seek services. However, it turned out the psychologists were very expensive. 'People with HIV and AIDS could not afford it', noted Mr Ragi. Eventually, the Kenya Red Cross stepped in to support PLHIV to access such services. Mr Ragi explained:

In the early days of response, there was no money. We took advantage of each other's position to move things. As an employee of Kenya Red Cross, I could access external information that was vital to those infected with HIV. People like John Nderitu or Esther who worked for Christian Health Association of Kenya [CHAK], linked those infected with HIV to hospitals. Dr Sobi Mulindi was at the University of Nairobi was to reach out to university students and other youths with HIV information. We had someone from AMREF, which was producing good IEC materials; then Action Aid boosted us financially, especially when it came to posting letters. Psychologist Kimani took care of psychological issues. We did that for five years. In the course of our work we operated closely with UNDP, who linked us to a group in Australia for support and partnership.

The buddy group did not have an office, and therefore had to hang around the Red Cross office. The place was important for sharing experiences, getting the latest HIV information from the Kenya Red Cross, and counselling. While the Red Cross office endeavoured to provide HIV information to Kenyans, Mr Ragi stated that there was little knowledge about HIV counselling in Kenya in the 1980s. The National Council of Churches of Kenya (NCCCK) then connected the Kenya Red Cross to Chikankata Salvation Army church, which pioneered a community-based AIDS programme mainly caring for the sick at home in Zambia (Mutonyi, 2000; Barnett & Blaikie, 1994; Campbell & Williams, 1992, 1996). The Kenya Red Cross borrowed Chikankata's counselling training materials and, in May 1990, conducted the first training of HIV counsellors in Kenya. The two-week training was comprised of the buddy group members who came to be known as the 'Group of 8' (hereafter G8), and a few nurses also received counselling training.

After the counselling training the G8 volunteered in health facilities to provide information, psychosocial support, and counselling to people with HIV and AIDS. They also advocated for de-stigmatization and non-discrimination of people with AIDS seeking services in various health facilities. They were their brother's keeper.

Onyango noted:

We were concerned about the mishandling of people living with AIDS in hospitals. We went to hospitals, talked to those who were hospitalized and made follow up when they were discharged. The government's budget for HIV and health was very minimal coupled with very limited staff. There was a lot of stigma and many people could not cope with the situation because they saw no hope. So when Joe Muriuki came out openly about his status, hospitals would refer people to the City Council clinic where Joe used to give counselling and support.

While they were concerned with the mishandling of people with AIDS, the important point here is the emerging resourcefulness of the G8 or people with AIDS in HIV interventions landscape. 'Organizations that heard about us found us to be very useful', noted Mr Muriuki.

External influence

The United Nations Development Programme (UNDP) and the United Nations Children Fund (UNICEF) learnt about the Kenya Red Cross's activities with the G8 and offered the latter group opportunities to share their stories for material gain. UNICEF and the Ford Foundation provided vehicles that enabled them to travel all over Kenya to raise awareness in schools. Such opportunities were a further eye opener that people with HIV and AIDS were resourceful and could engage in activities in terms of both providing support to one another and in engaging in various awareness-raising activities, and could get paid in return. Muriuki recalled: 'We got very excited when we realized we could educate pupils or students in schools, educate people in churches, and even in communities. We only talked about our own experiences of living with HIV'.

According to Muriuki, the first article about the G8 appeared in a local newspaper in 1990. Organizations and institutions got to know about the G8 and invited them to share their experiences as people living with HIV and AIDS in order to create awareness. While in the beginning they did not have material objectives, institutions invited them to give talks and gave them money. This quickly changed their objective. They strategically aligned

themselves to various institutions, in many ways commercializing their HIV status. They packaged and choreographed their stories into seasoned testimonials as ‘victims’ of infection, stigma, and discrimination. They aimed at heavily laden emotional testimonies. They mentored each other and few other newcomers on how to present personal testimonies that would appeal to different companies and organizations.

A board member of The Association of People with AIDS in Kenya, and a friend of Lenya, noted: ‘Based on the counselling and telling of testimonies that Lenya learnt from Mr Muriuki, he became very aggressive in conducting educational outreaches to companies and trade unions, by offering to educate the staff through his testimony. And for this he got paid’. The trading of well-crafted testimonies for material benefit is similar to what has been described elsewhere as confessional technology (V.-K. Nguyen, 2013, 2010). Nguyen suggests that in Burkina Faso testimonies were traded for medicines; in Kenya people sold their stories for money.

Over time, the G8 became known to government agencies, corporations, private companies, and churches and were invited and paid to give their personal testimonies while dispelling myths and misconceptions and sharing the information they had. The G8 were sponsored to attend international HIV/AIDS conferences where they learnt more about the disease and ways to engage with international community. This ushered them into the realm of global development. The UNDP sent representatives from the Kenya Red Cross and the G8 to the 1990 HIV/AIDS conference in Australia where they came in contact with other people living with HIV and doctors who became resources. With financial support from UNICEF, the G8 attended international AIDS conferences abroad where, according Mr Muriuki, they met with other groups and learned about organized PLHIV groups, rights issues, and how to conduct activism. They also became HIV expert patients. Similar to many other groups or organizations of people with HIV and AIDS in sub-Saharan Africa, the Kenyan group was not particularly radical in terms of politics (Iliffe, 2006). It was mainly through participating in conferences abroad that they learnt new ways of activism. That is also the time when the seeds of a support group were planted. Muriuki recalls:

We travelled to France, Britain, the Netherlands, and even Jakarta. We then came across support groups. We learnt more about organized HIV groups, but many were homosexuals. All the same, we became empowered. UNICEF took us to a meeting in France. They paid the air tickets, accommodations, and even gave us allowances. In France, we saw people carrying placards demonstrating in the streets; they slept on the roads demanding that governments

support HIV. We also went to the United States of America and learnt more about human rights. This was the first time people talked about human rights: I heard people say, 'we are human beings; we have a right to proper treatment'.

The international conferences provided the G8 and other people living with AIDS who joined them like Muriuki an introduction to (radical) international HIV activism that changed their perceptions and fortunes. It put them on the world map and earned them money as an international HIV activist group, resulting in the change of their perception of support groups, as they focused on opportunities. Apart from activism, conferences also allowed them to meet other groups and people, get information, develop networks and contacts, and explore funding opportunities. They were approached by international networks of people with HIV and AIDS in the North with funding proposals to conduct activities in Kenya and in the region.

Back home, the group adopted the more radical activist techniques they experienced during international conferences. They no longer wanted sympathy but were inspired to demand for human rights. They organized street demonstrations demanding their rights and held the first candlelight memorial. Muriuki observed:

From [international conferences] we learnt to be vocal. We spoke against discrimination in health facilities and workplaces. We organized our first candlelight memorial and invited the attorney general and lawyers. The attorney general told the lawyers present to write about human rights. The media became interested in our street demonstrations and activities.

However, the sensationalized reporting on their imported radical activism tactics did not work well for people with HIV and AIDS in Kenya. 'Rather than reducing stigma, media reports increased stigma toward people with HIV and AIDS', Muriuki explained. He added:

When we came back we organized street demonstrations and the media became interested, though they reported that victims of HIV and AIDS want to be kissed, hugged, and loved [chuckles]. That is what they wrote about us and I think it increased stigma. We educated the media on the language to use, like to stop referring to us as 'victims'. We were very open and the media was very open and followed what we were doing.

Beyond working with the media, the G8 continued fighting against stigma and discrimination: 'People with HIV and AIDS were suffering, and we needed to do more', Muriuki noted. Disclosing their HIV-positive status was both advantageous and disadvantageous to the members of the G8. They rose in prominence, both socially and within the world of AIDS intervention activities at home and internationally, and they began to speak about the importance of 'putting a human face to HIV/AIDS' to reduce stigma. This was rhetoric to which they were exposed when attending conferences abroad and from

several civil society organizations in Kenya. Putting a human face to HIV/AIDS was both advantageous and harmful; it allowed people to know HIV was real and increased awareness but also increased stigma more than before. Thus, as it seemed, going public was necessary for sending a message and creating awareness in the general community but not for stigma reduction or normalization of HIV. Muriuki explains:

In 1987 I was always sick and the doctor advised I take a HIV test. I tested HIV positive, my wife tested negative. My wife was pregnant. I was devastated, and especially as doctors advised I should not have children. When I tested positive, I only told my wife and we kept it a secret from my parents and her parents. I found it very stressful because there was no information. Slowly, I began disclosing my HIV- positive status to some of our extended family members. Most of them stigmatized me. Others discouraged me from advertising such a 'shameful' disease. My wife's relatives told her to leave me. But she stayed put. Stigma was too high that I felt for other people with AIDS. I wanted to share my experience with other people, both the infected and the affected. I publicly came out during a public HIV and AIDS campaign to put a human face on HIV and share my experience and encourage other people going through the same, to create awareness and educate people about the reality of AIDS. I also wanted to encourage others with the disease to be more open. However, up on coming out, my family faced negative consequences. People deserted me. Whenever I boarded a bus people would disembark.

In a story by Jemimah Mwakisho, 'Joe Muriuki's story is one of courage', that ran in the *Daily Nation* on 25 May 1990, Muriuki said he wanted to share his story with other people with HIV and AIDS who were scorned, ridiculed, helpless and depressed, put a human face on HIV, and create awareness about HIV/AIDS.

In 1992, with support from UNICEF, the G8 went on a learning trip to The AIDS Support Organization (TASO) in Uganda. At that time, TASO had received a lot of publicity about the work it was doing, and the Kenyan delegation learned a great deal from the visit, specifically, about TASO's structures and operations as a support group. The trip was a significant milestone in the history of HIV support groups in Kenya. Back home, as told by Muriuki, the Kenyan group was eager to implement some things learnt from TASO: 'We were too excited that when we got back to Kenya, we registered an organization. All along we were meeting as buddies, but we now focused on developing an organization'. They came up with the group's name – Know AIDS Society (KAS) – and elected their leaders. They included Muriuki (Chairman), Tom Ngunda (Vice Chairman), Lydia Wangeci (Secretary), Rawland Lenya (Vice Secretary), and Elizabeth Wairuri (Treasurer). Some of the pioneer members were Domitira Ndege, Azaria Omondi and Josphat Mutuku. All except Muriuki and

Mutuku have since died; Onyango, who was a key informant in this study, replaced Ngunda as Vice Chairman.

The election of leaders was quickly followed by a membership drive and, in May 1992, they registered KAS as a community-based organization with a membership of 120 people with HIV/AIDS. According to their charter, they aimed to provide a space where people living with HIV/AIDS could talk and encourage each other to be positive in the midst of hopelessness, offer one another psychosocial support, educate people with HIV and AIDS and the general public, promote self-help projects, and advocate for access to treatment in public health facilities.

The group first operated as an 'AIDS members only' organization but later opted to incorporate other people who were not necessarily HIV positive. 'They realized that experience with the disease alone was not enough; they needed other people who had the skills to work with, especially in proposal writing and accounting', noted Mr. Ragi.

The scramble for funding

The main aim of the group was to support each other, share personal experiences, and inform society about HIV. But the plot was soon lost. Ragi explains:

They started focusing on material benefits. We also noted a lot of power struggles. For some time, donors were not giving the government money, they preferred NGOs. As such, even the support groups and CBOs wanted to be NGOs. KAS met the key requirements, such as being a legal entity, and they were registered as an NGO. A number of factors seemed to be core in the formation of not only support groups but also organizations as a legal entity. Competition, money and leadership! While other factors might have been responsible for breakaway of groups and organizations, the bottom-line remained monetary benefit.

Even when the impact of HIV had become obvious in Kenya, international development organizations or donors did not fund the government due to fears of corruption, a dictatorial government, and a lack of political will. Donors did fund, however, civil society organizations to conduct HIV interventions (Prince, 2012). Furthermore, G8 made more contacts through conferences that allowed them to develop networks and access funding. Some of the networks and contacts urged them to form organizations as potential funding outfits for HIV interventions. However, donors could only fund legal entities like KAS. Like many others, Jemima, after hearing about KAS, left KICOSHEP and joined KAS because it offered peer-education, and income-earning opportunities.

Gaining access to money (either through direct funding or earned from giving testimonials) and international contacts was overall a good thing for individuals and many of

the early groups, but it also challenged the identities and intentions of most groups. The cash inflow led to group fragmentation and mutations. The groups got funded to offer more or less similar activities, mainly mitigating stigma and discrimination through educating communities, creating awareness, and offering psychosocial support. Some of the organizations offered emotional, social, food, economic, and medical support to people with HIV and AIDS and those affected.

‘The first person to break away from KAS was Mr. Lenya, in 1993’, recounted Ragi and Onyango. ‘He went on to form and register [as an NGO] The Association of People with Aids in Kenya (TAPWAK) after negotiating for funding from UNICEF and Humanitarian Aid (ECHO). Following the break up, ethnic differences started being visible among people living with HIV and AIDS. Lenya, a Luo, took with him many Luo members when he left KAS, while many of those who stayed behind were Kikuyus, loyal to Muriuki, a fellow Kikuyu. Jemima, a Luo, informed me that she too joined Lenya’s group. She was not comfortable to work with Muriuki whom, she alleged, favoured those from his community with peer education opportunities.

And the fragmentations continued. Suspicions were rife. Gradually, the objectives were changing. It was not long before a group of TAPWAK’s peer educators broke away to form Women Fighting Against AIDS in Kenya (WOFAK) with a gender dimension based on claims that women were most affected with stigma than their male counterparts. Ragi recalls:

After a trip for a feminist conference abroad, Dorothy, a female peer counsellor at TAPWAK, led other female peer counsellors and members away in what was described as a gender revolution to form WOFAK, of which she became the director. She registered it as an NGO in 1994.

The founding members argued that forming a women’s organization was the best way to deal with women’s issues. Stigma was very high and women were being thrown out of their homes. Many women registered with the group, where they met basically to support each other emotionally. They were able to speak out and raise their voices. Again, this new NGO got a lot of financial support from the government and donors. However, a critical assessment of reasons given by splinter groups for breaking away point to struggles for funds and power among leaders. Why, for example, would women opt to form WOFAK to fight for their rights instead of starting a department for women issues within TAPWAK? WOFAK²¹ was registered as a CBO and quickly rose to NGO status. Jemima, like other women, left TAPWAK to join WOFAK.

Despite the importance of gender in bringing people together to form new groups,

²¹ WOFAK became known for promoting positive living (good nutrition, and abstinence or use of condoms) and the use of vitamins and nutritional supplements among its members. For many years, it was famous for discouraging HIV treatment due to the toxicity of the drugs.

ethnicity led to the formation of another women's group: one of the TAPWAK members left and formed The Kenya Network of Women against AIDS (KENWA). Again, ethnicity and competition for resources were apparent. WOFAK was predominantly a Luo affair while KENWA targeted Kikuyus.

WOFAK operated in Kibera, Kayole, and Kariobangi before expanding its networks to (Luo) Nyanza province while KENWA focussed mainly on Kariobangi (Nairobi) and Central province (Kikuyu land). Initially, KENWA²² members earned money by offering their testimonies to different banks and government organizations' staff and the media. As they grew in size, they began to attract the interested of donors and eventually registered as a local NGO to qualify for funding.

The funding, in many cases, was blamed for divisions among group members, bringing about rivalry and competition to control resources. Some members earned substantial sums of money from their AIDS activities, moving up in social class and distancing themselves from other group members. Ragi alluded to monetary benefits being the main focus in a support group, and this led to a growing number of support groups quickly transitioning from CBOs to NGOs. As national-level NGOs,²³ they were in a good position to access funding and travel to international conferences.

Many group leaders lacked leadership and financial management skills. Ragi explained:

Most of them did not have capacity to develop proposals. As people with AIDS they did not see, initially, the value of incorporating other people who were not infected but were professionals. Some approached the Kenya Red Cross for skills development. They thought if you are HIV-positive you could not fit in their shoes, that you did not know how they feel and therefore could not run HIV project-related for them [] but that has changed and we have seen more groups being managed from a professional point of view. In 1994, we established the

²² The KENWA leadership was known for discouraging HIV-positive women from getting pregnant until the Asumpta baby boom. This changed after the director's economic status changed as a result of funding to her organization and she had three children. She had documentaries of her three pregnancies and deliveries of her children were in high-end private for profit hospitals in Kenya.

²³ NGOs offer a wider geographical coverage and more funding than the CBOs. For instance, from the Total War against AIDS (TOWA) funding kitty by National AIDS Control Council (NACC), national NGOs with wider coverage received funding range of US\$25,000–100,000. Those with district coverage received funds in the range of US\$5,001–25,000. And those with constituency coverage (where most support groups fall) received funding up to US\$5,000 (NACC, 2010).

Kenya AIDS NGOs Consortium (KANCO)²⁴ to offer capacity building and coordinate activities of the growing number of support groups and local NGOs working on HIV. We supported them directly or indirectly. We talked to them about leadership and capacity building. We also talked to donors to fund some of them through other organizations. A lot of donor funds came in, and this created further competition.

While fostering an atmosphere of national solidarity, the organizations simultaneously competed for resources and membership. Competition, conflicts, and infighting among the most senior members of groups often resulted in groups splitting up.

In the scramble for money and visibility, some of these early pioneers secured international jobs and funding. They became well known, wealthy and celebrities. As their social and economic lives transformed, they positioned themselves as key stakeholders and experts on HIV in Kenya, consolidating their leadership, networks, and economic power as ‘owners’ of the groups they formed. In ‘A People at War with Themselves’, an article that appeared the *Sunday Nation* newspaper on 1 December 1991 (World AIDS Day), it was suggested that there were many complaints in circulation about the people and organizations who were ‘glorifying AIDS’ for their own profit. The ‘war’ was between the average person with AIDS and those who were running the PLWA-led NGOs receiving donor funding.

Those running the PLWA-led NGOs became self-appointed spokesperson and representatives of PLHIV in HIV stakeholder HIV donor and implementation meetings, were portrayed as having lost their initial vision, moral grounding, and ethics by changing their activities to suit donors and to benefit as individuals. They seemed to be flying from one country to another to attend big international meetings²⁵. Along the way, they abandoned their support group members. Some members felt betrayed and dropped out to start their own support groups, while others, like Joseph, decamped to different support groups and organizations. And since some of the groups provided food baskets, desperate women continued to attend the group meetings.

Eventually, Kenya had more than ten national-level HIV NGOs and at least six national HIV networks. Some collaborated to form more support groups to expand their funding base. Others independently expanded their donor base for their organizations. Some key informants noted that some of the donors did not have monitoring and evaluation structures in place, and that group leaders lacked financial management skills. ‘There were no mechanisms in place for monitoring financial spending; consequently, misappropriation of

²⁴ Ragi left the Kenya Red Cross and became the director of KANCO, a position he held at the time of the study.

²⁵ This still happened at the time of my study. As noted in Chapter One, when I began interviews with key informants, the directors of local national HIV NGOs were abroad for meetings. I met a few of them at conferences.

funds was no big deal. Although funding sometimes came with trainings in financial management, this did not deter the moguls from misappropriating them', recalled a chief executive officer of a local national NGO.

With so much money and so little accountability, those who were savvy enough to appeal to the donors' goals capitalized on loopholes to misappropriate funds. They further created rifts among PLWA, making solidarities nearly impossible and led to feelings of helplessness among ordinary PLWA.

Donor funds intended for HIV support group activities were re-directed to set up private businesses, invest in real estate, educate children in universities abroad, and live luxurious lifestyles, among other things. Organizational resources were owned and controlled by local NGO moguls, who considered the groups and their funding their individual property. A co-founder of a local national-level HIV NGO said, 'I was a board member and a volunteer. The problem was to control the other founding member. . . . He used donor funds the way he pleased. . . . It was difficult to pin him down despite workshops by donors on good governance and calls for structures'.

Conflicts and tensions

The funding of HIV support groups reflected and constituted new meanings for and different perspectives of the groups, and new forms of relations, conflicts, and tensions. The gains of the moguls helped to create an atmosphere of powerlessness and resistance among ordinary group members. Some, like Ragi, became very frustrated: 'Most organizations were owned by individuals. . . . They did not allow outsiders to be part of leadership. This became a cash cow especially where the owners were a family; the man or wife is director, the wife or husband, the co-director and the children the secretariat'. This observation resonated with Jemima's, who told me that when money started coming in, 'Muriuki made KAS like a family affair, him and his wife'. Some group members were infuriated.

As the secretary of KIPOTEC noted, people living with HIV did not understand project money, and they felt any HIV funding was their money to be dished out by them. The director of KICOSHEP, who was a nurse by profession and not HIV positive, told me how she was confronted by people living with HIV over project money:

They claimed, 'This is money for HIV. It is our money'. They can even beat you, and they talk negatively about you. They come and see what I have done and say, 'How come you can be able to have such a facility? You have taken our money'. They refuse to understand. They always think there is HIV money and people like us who run projects are not giving them their money. You have to work around them and make them understand the money is for projects.

Similarly, Ragi noted, ‘they [PLHIV] come to an organization like KANCO and see my balance sheet, then they ask, “what is in it for us, these guys have money” and if you do not give them then they claim we are taking their money’.

To a certain extent, it was believed that moguls’ misappropriation of funds was facilitated by donors, and some blamed the donors for creating inequality between the moguls and other people living with HIV and AIDS. According to one key informant, ‘The donors had the founder member syndrome. . . . They only trusted and did business with the founder of the groups/NGOs. . . . Some donors never thought beyond the founder members’. Only moguls met the donors, and only moguls were invited to international meetings and conferences. They both *were* the networks and they *had* the networks. Other people living with HIV never understood why most donors never reached out beyond the clearly corrupt moguls. One chief executive officer of a local NGO painstakingly described how some donors did not have confidence or trust in the organization, but only in the individuals known to them. According to the TAPWAK director, a donor representative expressed his concern about organizational leadership and even withdrew funding following the death of the organization’s leader:

I was employed as an accountant following a donor’s demand. In 2008 and 2009 when the founding member began ailing he delegated many duties to me. I could do everything but put him in the picture. In 2009, when he passed on, we quickly convened an urgent board meeting . . . that was aimed at ensuring the organization exists beyond the founder. After the death of the founder, one Canadian donor called to find out if the organization still existed. When it was time for the call for proposals we applied but they never replied to us. I later called and they said they would come to see our capacity. They came and said they thought the organization died with the founder.

The inability of donors to see organizations beyond founders and the inability of other people with HIV and AIDS to secure funding opportunities were usually blamed on moguls who were accused of withholding information about opportunities and of preventing group members from meeting with donors. While moguls were working and were entitled to earn a living from the funding they received, some key informants characterized moguls’ obsessive yearning for money as a reflection of Kenya’s corruption at the time (Maathai, 2007), and also of donors failing to institute accountability measures. The moguls had come in contact with corruption and government officials. And like those officials in power, HIV group moguls were described as opportunists who took advantage of the people they mobilized in order to acquire funding, which enabled them to benefit individually and climb the social ladder.

Curiously, some key informants give credit to moguls for, seemingly, leading the HIV

response as others (government, international NGOs, donors) followed. Ragi, on the flip side, gives credit where it's due:

Even as many of their peers died quickly, they were able to advocate for issues affecting people living with HIV, so they are at the top of decision making as opposed to being an expert talking on their behalf. They were the people who braved stigma and discrimination, and put a human face on HIV and AIDS in Kenya. They were instrumental in putting HIV in the public sphere, and relentlessly educated communities about HIV/AIDS, and advocated for the rights of people living with HIV in Kenya. ...Their organizations continued to perform some of their initial activities that were considered fundamental, such as encouraging disclosure, providing food baskets or lunch, engaging in income-generating activities, and communicating the right messages.

Onyango, a CEO with a local NGO said:

Some people take support groups for granted because they do not know what the groups are for. It is quite unfortunate that people relate support groups with people who are not educated or professionals. . . . You are looking at how support groups have helped human beings, you want to see how another human being has helped another human being. They have put a human face to HIV. The Onyangos, Lenyas, Asumpta, Joe, etc., who came out and talked to people face to face and through the media, putting a human face on HIV, have helped so many people, even the professionals, to realize with HIV you can live even when we could not go far in advocating for availability of cheap treatment.

The moguls showed a remarkable capacity in mobilizing people living with HIV and AIDS and providing them with a space to meet with others, share experiences, and provide and receive emotional support.

Conclusion

I have shown how support groups were not only a product of internal and external factors but rather an intersection of factors. It is clear that HIV radically altered social care and support structures in Kenya. This desperate context contributed to the emergence of new social relations and groups in the pre-treatment era that hijacked the role of the society to protect people with HIV and AIDS. People with HIV and AIDS came together in response to a failed state and societal responsibility in the face of life-threatening conditions. Other conditions such as social issues and a lack of information were recipes for the emergence of HIV biosocial relations.

Motivation of people with HIV and AIDS from different demographics to participate in support groups differed. Those from the upper and middle classes were more concerned with access to treatment while those from the lower-middle and low class were after psychosocial and material/economic support, and fighting against stigma and discrimination. In addition, stigma brought about both visibility and invisibility. Unlike the PLHIV from a low class background who braved stigma to benefit from various opportunities and play a role in HIV interventions, among the middle-upper class, HIV and social class related stigma threatened the participation in support groups and HIV interventions. They could not join in HIV activities that would expose them.

I have also shown how different logics of care and support emerged and shifted. Support groups promised opportunities. The chapter has demonstrated a clear commercialization of individual HIV positive identity for monetary gain, and the struggle for control of resources altered and interfered with the objectives and meanings of support groups. The obsession of many moguls with HIV funding should not be seen as unique, as corruption had taken root in Kenya. I have also shown the initial objective of such groups' formation was to create spaces for PLHIV to receive and provide compassion to one another, and share HIV-related information, if any. However, practical needs combined with financial opportunities, and the culture of corruption that was prominent at the time in Kenya shifted the objectives of those leading the groups as well as the group members. HIV funding provided employment and entrepreneurship for HIV moguls who established organizations, and the beginning of NGO-ization of HIV. However, the contention over the use of money and the accumulated wealth of organizational leaders resulted in conflicts, tensions, breakaways, and mutations of HIV-related organizations.

CHAPTER 4
TREATMENT ERA: A TIME OF SUPPORT GROUPS'
PROLIFERATION AND DECLINE

Introduction

People living with HIV join support groups based on the gains but if it is just a place where other people get to know my status, I would rather keep it a secret. It has to do with direct benefits such as school fees and food donations, which put off the middle class. But it depends on the definition of benefits. If a support group is not beneficial people will not join.

(International NGO Staff)

Distinguishing between two sets of PLHIV individuals – the low income and the affluent – was inherent in some key informants' observations on participation in HIV support groups. This distinction drew a direct link between the economic insecurity or vulnerability among lower class people and pursuit of material needs (money, food, etc.), and between the social insecurity of the affluent class and emotional and social support. These are some of the divergent factors that account for participation in support groups.

By the late 1990s, numerous HIV support groups emerged in Nairobi. They received a lot of international funding. However, around 2009, this funding began to decline, and that led to a decline in the number of support groups operating in Nairobi. This chapter traces the rise and fall of support groups in Nairobi and examines various policies, technologies, and institutions that have shaped these trends. In various ways, HIV funding streams and HIV-related technologies, most notably simplified antiretroviral treatment regimens, have combined with on-the-ground social conditions and the state's response to HIV to contribute to the proliferation and decline of support groups, both those affiliated with community-based organizations and with public health facilities.

In describing how the influence of HIV funding and technologies intersect with different actors (PLHIV individuals, support groups, organizations, and donors) to shape care and support initiatives, I focus on three time periods: the end of the national disaster (1999-2002), resurrection (2003-2008), and normalization (2009-present) to demonstrate the changing face of HIV support groups. I explore several concerns related to patient responsabilization, materialization of support groups, and normalization.

The first period begins with the tail end of AIDS as a national disaster, when the effects of HIV and AIDS had become so devastating that the state could no longer look away. In 1999, HIV was declared a national disaster, paving the way for an organized HIV response within Kenya and, importantly, in partnership with international donors. HIV testing began to

be increasingly promoted in community-based health centres and in public health facilities. Support groups moved into health facilities.

The second period began when HIV treatment arrived in Kenya, accompanied by massive funding schemes that specifically encouraged the growth of civil society and community-based care initiatives. Saving lives was the main focus. During this period, support groups proliferated and most of them were driven by HIV funding to carry out specific care-related tasks. The most recent period, 2009-present, has been marked by a discourse of normalization. International organizations and donors have begun to speak of ‘the end of AIDS’ and funding for HIV has significantly declined. Every year, many HIV patients are put on treatment, but international funding is no longer increasing. With the ‘crisis’ under control, the expectation is that the Kenyan government should shoulder the burden of treatment, care, and support. Lately, much of donor support focuses on high-risk groups (so-called key populations) besides funding the adherence-focused support groups in health facilities. In this era, many community-based support groups have either closed down or shifted towards income-generating activities in Kibera, while the groups at Kenyatta National Hospital became highly medicalized.

National disaster and response (late 1999–2002)

During this time, media reports put the AIDS-related death toll between 500 and 700 per day (UNAIDS, 2000; *The Daily Nation*, 3 May 2001). This could have been underestimated due to unreported cases in rural areas. Secondly, the state’s denial and corrupt response to HIV had become untenable. Prior to declaring HIV a national disaster in late 1999, the Kenyan government had undertaken minimal responses to HIV and AIDS (chapter 3). The declaration of HIV as a national disaster marked a significant juncture in the HIV response in Kenya, and, as a result, HIV began to be clearly articulated as a development issue.

The state began to display the ‘political will’ deemed essential by international aid agencies and, consequently, massive funding began to flow into Kenya for HIV prevention and mitigation (World Bank, 2000). The norms included a mandated multi-sectoral response and the inclusion of people with HIV and AIDS in the implementation of HIV interventions. The state’s engagement with and involvement of civil society organizations came with the establishment of the National Aids Control Council (NACC), which derived its multi-sectoral approach from UNAIDS advisors and guidelines that considered community inclusiveness.

Meanwhile, strengthening civil society was the main goal of donors in this period. Most donors believed that the Kenyan government was too corrupt to be trusted. This meant a lot of donor funding was channelled through civil society organizations to support HIV treatment, care, and awareness-raising campaigns.

In 2000, the Kenyan government signed a US\$50 million Development Credit Agreement with the World Bank to fund the four-year Kenya HIV and AIDS Disaster Response (KHADRE) that was to bring together various stakeholders, including development partners, government structures, and civil society organizations²⁶ (World Bank, 2000; NACC, 2010). KHADRE allocated US\$30 million to community-based organizations, the private sector, and research initiatives (World Bank, 2000). Most of these funds were channelled to community-based activities to provide care and support in areas that were not being reached by the government. This, as noted by Mr Ragi (the director of KANCO, see chapter 3), resulted in an increase in HIV support groups and CBOs, and an emergence of what Prince (2012, p. 16) referred to as ‘the NGO economy’. The number of PLHIV-led NGOs also grew. People with HIV and AIDS were mobilized in groups purposely to share experiences, create awareness and educate communities, provide home-based care services, stigma reduction, HIV prevention, and economic empowerment. Some groups received direct funding from donors, while others got funded indirectly through international NGOs.

The move to involve PLHIV in the HIV response in Kenya coincided with the global inclusion strategy known commonly as the Greater Involvement of People with AIDS (GIPA) initiative, which focused on creating opportunities for people with HIV/AIDS within the policies and programmes designed to serve them, as articulated in the NGO Code of Good Practice (www.hivcode.org HYPERLINK "http://"). While donors strongly encouraged the involvement of ‘stakeholders’ or representatives of PLHIV, those PLHIV who were already gaining public prominence in Kenya made the most of their new stage, using international activist discourses to demand a space for PLHIV in Kenya’s unfolding national response. The people who came to represent Kenya’s PLHIV at the national and global level were mainly the HIV moguls and their networks, which were uniquely situated to step into this gap. As they advocated for GIPA initiatives to be integrated in Kenya’s AIDS response, they also set the scene to accrue enormous personal material benefit, power, and status.

From post-test clubs to support groups, collective response to health and material needs:

Emergence of HIV support groups in Kenyatta National Hospital

After the declaration of HIV as a national disaster, both HIV testing and support groups expanded within the health facilities and in the communities. In health facilities, where HIV testing was readily available, post-test clubs were established for people testing both positive and negative. As antiretroviral treatment was not yet available, these clubs, essentially those

²⁶ Civil society organizations include CBOs, NGOs, UN agencies, faith-based organizations, foundations, and PLHIV group and networks. These are organizations that advocate for the interests of their members of the groups they represent (Warwick & Voitzwinkler, 2014).

that focused explicitly on health (rather than economic) issues, centred on HIV prevention. They provided basic information about HIV to members who were encouraged to take the information back to their communities.

In 2001, in a 7ft by 7ft room, a Voluntary Counselling and Testing (VCT) centre was opened at Kenyatta National Hospital's Patient Support Centre.²⁷ After undergoing tests, people wanted more information about HIV, so the department decided to provide information to all those who visited – whether they tested positive or negative. With knowledge gained from a tour in Uganda²⁸ and financial support from USAID through Family Health International,²⁹ the first post-test club was formed in KNH's Patient Support Centre. The head of the KNH Patient Support Centre recalled:

We used to have so many people come to VCT and some others were referred from the wards and other health facilities. We decided, 'why don't we have a group, listen to them and address their concerns/questions'. We found it to be effective tool in cost, quality, and quantity. It was a cheap and economical way to provide a service, and it became popular. While the post-test club was effective in reaching many people, however, we found the large numbers to be chaotic and that those who tested positive needed more support than those testing negative.

The KNH VCT manager noted that the need to attend closely to those who tested positive resulted in the establishment of HIV-positive support groups:

Some of them, after a group session, stayed behind to discuss personal issues that they did not feel comfortable sharing in post-test clubs for fear of disclosure, while some requested to meet separately from HIV-negative testers. We realized they needed more support. That is how we decided to have HIV-positive support groups.

This changed the concept and aim of post-test clubs as well as the content of what was addressed in the group sessions, evolving from post-test clubs to HIV support groups. As defined by a member of Family Health International's staff, the 'support group was for people living with HIV, and post-test clubs were for people who tested, whether negative or positive'. The group sessions were no longer primarily about offering general information about HIV and promoting HIV prevention. Support group therapies included sharing personal

²⁷ Since 2014 the unit is called KNH Department of Mental Health.

²⁸ Before the opening of the VCT centre, KNH staff were among the beneficiaries of a learning tour to The AIDS Support Organization (TASO) and AIDS Information Centre (AIC) in Uganda that was funded by USAID.

²⁹ Now FHI 360.

experiences to battle self-stigma and encourage hope, providing information about treating opportunistic infections, sharing tips on disclosure, providing more detailed information about HIV, sharing recommendations for improving longevity and health in the absence of antiretroviral treatment, and providing information about living positively (safer sex and good nutrition).

From professional to peer facilitation

Unlike most health settings in Kenya at that time, KNH was privileged to have psychiatrists and psychologists who initially provided HIV information and chaired group sessions. Most public health facilities were experiencing a human resources crisis, while being simultaneously overwhelmed by the number of AIDS patients in the wards. KNH was also hard hit by HIV (Arthur et al., 2000). As a referral health facility, KNH received the highest number of HIV/AIDS-related patients from all over the country. In many cases, the health workers who were charged with facilitating the support groups were too busy with other core duties. As more and more people tested for HIV, the demand for support groups increased. Although there was a demand from patients to run support groups on Saturdays when they were not working, the FHI programme officer³⁰ overseeing KNH VCT and Care noted, 'Some health care staff provided support services but even then, people had competing priorities. It was not working very well, and it varied from place to place'.

The KNH staff developed an in-house curriculum to train support group members in group formation and facilitation skills. A few PLHIV who attended the trainings became peer educators and were tasked with facilitating support groups while KNH health care workers assumed the role of co-facilitator.

From facility to community

Appreciating the effectiveness of group therapies – both in quantity and quality – the head of KNH Patient Support Centre noted that the centre's staff encouraged the replication of such groups in communities to meet the increased demand and also encourage communities to accept people with HIV/AIDS. More PLHIV were trained as peer educators by the KNH staff to take support groups to their communities. Quite often, they linked people in the community to health care services and made follow-up visits to patients in their homes. They

³⁰ She had previously managed AIDS Information Centres (AIC) in Uganda. Her role was to guide the implementation of post-test clubs in KNH.

also linked patients to CBOs that were providing economic assistance. In addition to medical benefits, support group that emerged were also important in building social networks (Desclaux et al., 2004).

Materialization of support groups in Kibera

With the government doing so little for those infected with HIV, development organizations began rolling out massive funding initiatives. With HIV funding making its way to HIV-affected communities, people living with HIV and AIDS started to be visible in public through support groups. These groups played an important role in helping people living with HIV to survive in different ways.

MSF Belgium arrived in Kibera at in 1996, shortly after triple combination therapy had been discovered in the West, but long before it became widely available in Africa. In Kibera, there was no treatment due to prohibitive prices. From 1996 to 2002 MSF focused on providing psychosocial and palliative care to people with HIV/AIDS in Mbagathi hospital and Kibera. They established a programme that linked the health facility and the community, in which health workers were trained to go into communities and offer services such as counselling to people with AIDS and their families. MSF also organized informal patient groups (irrespective of health condition) in Mbagathi hospital, which were facilitated by health professionals and, later collaborated with Know AIDS Society to introduce PLHIV-facilitated groups. Despite MSF Belgium's efforts to strengthen family-based care, caring for people with AIDS continued to be a major challenge and a crisis for families, especially in Kibera. People with AIDS need material help out. By 2002 material support from outside began to trickle in.

A member of the MSF staff, who had previously worked for Riara, recounted:

In 2000, the Riara organization began offering food donations to people with HIV and AIDS. These donations attracted many people and resulted in a support group with over 200 members. The group was facilitated by social workers and aimed to address the practical needs of members, including food and providing tuition fees and uniforms for the children of people with HIV and AIDS. At that time, people were focusing on surviving with HIV and AIDS for as long as possible. ... By providing material things [in Kibera], it was perceived that support groups are where people only get material aid. And therefore support meant material support. Access to material needs for survival became the main focus.

Meanwhile, KICOSHEP (see chapter 3), focused on psychosocial support and welfare, increased the number of support groups to accommodate more people living with HIV and AIDS.

A time of resurrection (2003–2008)

According to key informants, the historical conjecture of HIV funding and treatment was marked by the proliferation of NGOs, and support groups. Even as the availability of treatment made significant contributions, Mr Ragi, KANCO's chief executive officer attributed this proliferation to massive donor funding: 'Groups increased from 2000 due to World Bank funding, and by the year 2005 they became a forest'.

In 2003, the WHO initiated its '3 x 5' target, with the ambitious aim of getting 3 million people living in low-resource countries on antiretroviral treatment by 2005 (WHO, 2003b). Although the target was not met, it set the stage for what came to be known as treatment scale-up in many African countries, including Kenya. The global promotion of free HIV treatment profoundly transformed the Kenyan HIV response. However, the assumption that with treatment available, people with HIV would automatically get on treatment (Moyer & Hardon, 2014; Moyer et al., 2013), was, to some extent, a fantasy. People with HIV and AIDS were confronted with a number of challenges including stigma, loss of income, and lack of social support, food, and information. These factors affected their ability to seek out treatment. PLHIV who were eligible for treatment needed support. Support came through NGO, CBO and support groups.

Growth of a local economy of NGO/CBOs

Life-prolonging treatment, accompanied by even greater levels HIV funding, brought different perspectives, meanings, expectations, and donor and biomedical agendas. People living with HIV expected physical, economic, material, and psychological relief; donors expected value for money; HIV biomedical interventions expected the responsabilization of PLHIV; the government expected outreach to PLHIV with various services; NGOs expected to obtain financial support for HIV programmes; and communities expected HIV interventions.

The prolonging of lives became the main goal for all players in the HIV response.

This meant getting people to test for HIV so that those who tested positive could be enrolled in and kept on treatment programmes. The success of treatment programmes required counselling to encourage adherence, disclosure, and good nutrition, all of which could be accomplished effectively through support groups (Simbaya & Moyer, 2013). The groups relied on biomedical and social norms to instil patients' responsibilities, enhance treatment adherence, and halt new HIV infections (Marsland, 2012). The need for successful HIV treatment outcomes and the availability of colossal funding in this era led to mushrooming of support groups in both public health facilities and communities.

Importantly, 2003 was the year that United States President's Emergency Plan for AIDS Relief (PEPFAR) was established through the initiative of President George W. Bush, with its unmatched and morally charged funding (Epprecht, 2013). The other main funding mechanism to accompany treatment scale-up was the Global Fund to Fight AIDS, TB, and Malaria, which had been established in 2002. Both PEPFAR and the Global Fund directed aid to PLHIV-run organizations through an express commitment to expand civil society in Kenya. Rather than giving money directly to the Kenyan government to develop a national treatment programme, PEPFAR primarily channelled funding through partner organizations, many of which were American-based, including international NGOs such as the Program for Appropriate Technology in Health (PATH), Pathfinder International, the United States Centers for Disease Control and Prevention (CDC), Family Health International (FHI360), HIV/AIDS Management Science for Health (MSH), and the Johns Hopkins Program for International Education in Gynecology and Obstetrics (JHPIEGO) (OGAC, 2004).

Mr Ragi, who, for the last two decades, has overseen the civil society HIV response since the inception of the first PLHIV group in Kenya known as Know AID Society (KAS), and has been at the helm of a consortium of HIV and AIDS groups (see chapter 3), recounted how donors from the North came with their own NGOs. He recalled, 'They moved from their capitals in the North to the streets of Nairobi and into the villages of our country to implement HIV programmes'.

One area that received a lot of attention in the early years of treatment scale-up was the promotion of the 'prevention with positives' programmes,³¹ mainly focused on self-care

³¹ Prevention with positives refers to prevention efforts that support HIV-infected persons to reduce the risk of HIV transmission and re-infection (NASCOP, 2014, p. 13). In addition, helping HIV- positive persons achieve and maintain physical, emotional, mental, sexual and reproductive health, economic stability and well-being; and to assist those HIV positive persons

in treatment adherence and HIV prevention (NASCOOP 2014, 2008b). Support groups were used to distribute messages that specifically promoted the notion of positive living (safer sex, treatment adherence, treatment of opportunistic infections, balanced diet, family planning) for the purposes of creating what was termed ‘a competent community’ to halt new HIV infections (Stene et al., 2009; Gupta & Fisher, 2009; Parkhurst, 2013; Hargreaves, 2013). A NACC staff told me that the aim of encouraging participation in support groups was to create a competent HIV society where members were to help each other in monitoring treatment adherence as an important factor in the management of the disease.

The task of reaching PLHIV could not be done only by international NGOs. PEPFAR also directly funded local organizations such as the Catholic Church’s Easter Deanery AIDS Relief Program (EDARP) and the Kenya Network of Women with AIDS (KENWA) in Nairobi. However, international NGOs with HIV funding sub-granted support groups to provide care in the communities (Johnson, & Khanna, 2004), following up with patients who had stopped treatment, distribute *msaada*, and providing treatment literacy trainings and general psychosocial support to encourage adherence, positive living, and treatment success. Group members who participated in such activities were paid allowances.

Other donors supported support groups and NGOs, including local ones. The Global Fund supported CBOs such as KENWA and Sanaa Arts to provide home-based care and HIV-prevention activities, respectively. With the support from the European Union, Mildmay Kenya facilitated support groups in Kenya prisons among others. PLHIV-led NGOs³² received funding from multiple sources to conduct HIV-related activities in communities. In addition, other bilateral involvement from other countries (Japan, Sweden, etc.), and international HIV activists, also tried to shape the Kenyan response to encourage the active involvement of PLHIV. For example, the International Treatment Preparedness Coalition (ITPC) worked with the East Africa Treatment Movement (EATAM) to fund community-level HIV support groups to conduct treatment literacy trainings that went beyond treatment

who do not know they are positive in learning their HIV status when they are ready (Harder+Company, 2009, p. 1).

³² These included the Foundation of People Living with AIDS in Kenya (FOPHAK), The Association of People with AIDS in Kenya (TAPWAK), Women Fighting AIDS in Kenya (WOFAK), Know AIDS Society (KAS), Network of People with AIDS in Kenya (NEPHAK), Kenya AIDS Consortium (KANCO), Movement of Men against AIDS in Kenya (MMAAK), Kibera Community Self-Help Programme (KICOSHEP), and Society for Women with AIDS in Kenya (SWAK).

adherence to encourage PLHIV to advocate for better and sustained access to treatment. Such an environment precipitated growth and participation in support groups.

Medicalization and msaada at KNH

While recognizing that PMTCT support groups might have emerged in KNH earlier on (see chapter 2), the attention of key informants seemed on the bigger picture. Around 2004 and 2005, FHI supported an initiative to supply ARVs to a number of adult patients at the hospital. A year later, the CDC-funded AIDS, Care, and Treatment Services (ACTS) programme began providing ARVs to children. Finally, in 2006-7, free HIV treatment was made available to patients at the hospital. With increased treatment, support groups at KNH focussed on nurturing responsible HIV patients who would adhere to treatment and prevention of new infections.

However, members were mainly encouraged by allowances, provision of tea and snacks, food, transport, and other benefits. The more money given, the more they attended. The high number of attendees necessitated the formation of more groups. As a rule, groups were limited to accommodate between 15 and 20 members to ensure proper facilitation. A peer mentor at the KNH support group recalled:

Attendance in KNH support group was overwhelming when there were transport reimbursements. A session would have over 60 members in one group. We had to split them into several groups, each with 15 members. But the number of those attending the groups reduced drastically when the transport reimbursement was terminated. The majority who came from Kibera were after the money. We knew this because there were so many support groups in Kibera, and quite a number of them were not even KNH patients. Terminating transport reimbursement meant a person had to go somewhere else where they could get the money for family. Coming to support group was not a priority when there was no money.

On the same topic, a former KNH peer educator, and now currently chief executive officer of a local PLHIV NGO observed:

In KNH, there was a time when we were giving people transport allowance, supplements, teas – then you find there were people who would go from one support group to another seeking handouts. That is why professionals did not want to be associated with support groups. There were people who knew when support groups were in session and what support groups

provided. They would know, 'this one does not provide fare, but if I go there I would get tea'. They would know, 'this group does not provide this, but you will get nutritional supplements', or it does not provide this but you will get this, so in a month or a week they will just be revolving through these groups. ... In KNH when we provided incentives, we had a huge turnout and when we stopped the number reduced and actually we did not need to have more than 20 people in a support group. But in some support groups in the community you would find more than 100 members in one sitting who come to eat, get handouts, but they would gain nothing in terms of psychosocial support.

A staff member of a community-based organization who attended a KNH support group noted:

Some of the people were very hungry and you know when someone is hungry, they really cannot concentrate and it was a motivation for them to come in big numbers. ... Because the people we handle are very, very poor in that when you talk to someone about nutrition without providing the food it is doing them disservice. ... So we provided them with something small – KSH 200 – to support them on that particular day and it motivated them to come in large numbers the following day. The end result was that we were able to reach many people with HIV information. ... We asked them if we should buy food for them or give them money, and everyone said they wanted the money to use for their families.

PLHIV needed food as much as they needed ARVs (Prince, 2012; Kalofonos, 2010; NASCOP, 2007, 2008a).

At the time of my research, usually, the number of support group membership ranged as high as between 15 and 24 but fluid levels of participation in most groups. The support groups at KNH were not offering transport allowances. Funding had been reduced and KNH only offered bread and tea. However, the hope for material assistance among PLHIV remained. One of the support group sessions I attended regularly at KNH was for discordant couples. I attended eight sessions, each of which had between four to nine regular group attendees. However, when I arrived for the ninth session 17 people were in attendance. Before the session started, the subject of *msaada* was brought up by one member:

Member 1: I was called to attend the support group, are they giving us something?

Member 2: I don't know. I was called too.

Member 3: I was also called. Maybe they have '*something*' for us. If they do not give us '*something*', I will not come back again.

Member 2: I was told the funding came to an end – that is why they stopped giving us

'something'. If they do not give us then I will also not come back.

Member1: If they do not give us *'something'* I will not come back to waste my time here.

After the group session, during walking session I talked to one of participants and asked him about this *'something'*. He responded: 'Support groups were meaningful when they used to give us KES 200, but now they do not give us anything. I cannot leave my business or errands just to come and waste time. When I was called here, I thought there was *something*, now they did not give us anything, I will not come back'. A peer mentor in our company noted: 'That KES 200 [transport allowance] was really something to many people. ... For one who did not have food and maybe is the family's breadwinner, going home with the KES 200 (equivalent 2 euro) meant food for the family'. Indeed, in the next and subsequent group sessions, only regular group members were in attendance.

HIV treatment and msaada in Kibera

By the time HIV treatment reached people in Kibera, it was a crisis. Those with AIDS were very sick, incapacitated, and dying, and social support systems had become fragile. MSF Belgium was the first NGO to provide free ARVs in Mbagathi Hospital, located near Kibera. Later MSF expanded ART provision to clinics inside the slum of Kibera. At that time, there was low adherence to HIV treatment. As such, MSF Belgium introduced new approaches to encourage treatment adherence. They included biological eligibility and having a 'treatment buddy' who would be expected to support their adherence, besides agreeing to join and actively participate in a support group. 'Treatment buddies' were offered treatment literacy training, which was presented as the 'tenth commandment' of MSF literacy training. It further encouraged them to form treatment-oriented support groups for not more than 15 members. Each fortnight, MSF provided treatment literacy training to 40 or more PLHIV, referring them to existing support groups or encouraging them to form new ones, and this resulted in the growth of more support groups.

However, MSF Belgium's intent that support groups should provide psychosocial support was distorted by the community's definition of 'support' as *msaada*, or material aid. For most people, support groups were seen as spaces to access material resources, which often meant a significant deviation from MSF psychosocial support intent. A MSF Belgium staff person told me:

When MSF Belgium in Kibera and Mbagathi District Hospital started offering ARVs, they initiated and facilitated support groups for psychosocial support and continued treatment literacy. During this time, many people living with HIV were bedridden or physically too weak to fend for themselves. Initially MSF Belgium provided some food to some patients. Other organizations such as World Food Programme, UNICEF, and Child Life International brought in *msaada*. Although MSF intended the support groups for treatment adherence through continued treatment literacy and psychosocial support, it seemed many people in this locality were more interested in *msaada*, which became a source of income – because of how people interpreted ‘support’ to mean ‘material support’.

The MSF staff member further told me that as the *msaada* concept gained roots in Kibera, MSF dropped the term ‘support group’ and adopted the term ‘post-test club’ to make it clear they were not in the business of offering material support. However, as observed by other support group leaders in Kibera, only the name ‘support group’ changed, but its practices remained the same.

‘Umechalewa’ (you are late): the golden days

Between 2003 and 2008, I witnessed the growth of support groups, especially in Kibera. By 2010, when I began my fieldwork, informants in Kibera commonly told me that I had ‘come too late’ to study support groups (see chapter 2). The golden days of 2003–2009 had passed. Of course they did not know I had been around, and I let them tell me about those golden days of HIV support groups. For example when I introduced my study to the chairman of the Kibera Post-Test Club (KIPOTEC), he replied: ‘*umechelewa*’, or ‘you are late’.

He told me that HIV support groups were very active between 2003 and 2009, and this was when many HIV/AIDS patients were bedridden and abandoned by their families. He said:

I was one of them. Those of us who had been bedridden were visited by PLHIV who offered home-based care services and were taken for treatment at the MSF clinics here in Kibera. Once you got better you volunteered to help others who were bedridden. We literally resurrected so many people. We used to visit houses and find isolated people. They had soiled themselves and we washed them. We cooked food and fed them. We took them for treatment and took care of them until they walked. Support groups were very effective here in Kibera. Now people have gotten better and moved on with their lives, [and] bedridden cases are few.

The notion of ‘my brothers’ keeper’ was at work between 2003 and 2009. Home-based care was one of the primary activities that support groups carried out as a way of ‘paying back’ those who had ‘resurrected’ them, but also because support groups were funded to do this kind of work in this period. According to chairman’s perspective, at the time of my study, support groups had declined because there were fewer sick people and less need for home-based care. However, the demand for home-based care continues into the present. According to Dr Cherutich, a former NASCOP, funding was available but less utilized. As I show shortly, local NGOs that previously offered home-based care were now offering health-facility based home-based care.

The KIPOTEC chairman’s claim that I was late to conduct a study on support groups was echoed by others. On subsequent days, as he introduced me to support group leaders, he was always interrupted when he mentioned the topic of my study. Sayafu interrupted to say:

Umechelewa (you are late). You should have come between 2004 and 2008. Support groups were very active then. Many people joined support groups including those who were not HIV positive because of the food donations that came through the groups. People came to the groups with very big paper bags, much bigger than your bag here. ... They came to get *unga*. And if the groups did not provide *unga*, be sure they would not come again; they would go to another group where they would get free *unga*. ... People were registered in so many groups to have access to any *msaada* available.

The chairman then added:

Kibera was full of support groups those days. This was a source of livelihood, even when people’s health improved. Many of them moved from one group to another because of material support. They did not need casual jobs because they could access *msaada* through the groups they were registered in. But now there is no *msaada*, and when I call them for meetings very few attend.”

One of the CBOs in Kibera, known as HAKI, uses a business model and runs a network of savings and loans for over 50 groups in Kibera. It also runs other activities such as trainings on gender-based violence and HIV treatment literacy, provides support to orphans and vulnerable children, and sponsors several support groups. Regarding the significance of the ‘resurrection period’ in Kibera, the HAKI chief executive officer said:

This was a time when we had a lot of material support such as food, school uniforms, and money. At HAKI, for instance, we received food donations from Germany and other places and we opted to cater for orphans and vulnerable children. We had a lot to give out. People

did not have time for HIV knowledge empowerment and psychosocial support: they joined as many support groups as possible that provided material support. We also had organizations that specifically provided food to bedridden patients on ARVs until 2008 when they withdrew.

In my conversations with some support group members, I gathered how *msaada* and home-based care job opportunities not only saved but also ‘resurrected’ lives. In the Kwa DO support group, as we waited for the group leaders one day, members recalled that many people were dying and experiencing extreme physical impairment. Many people with AIDS were bedridden, abandoned in their houses to die. Using donor funding that came through NGOs, support group members were able to offer the bedridden home-based care services. They humorously reflected and demonstrated how they struggled to walk to attend sessions. One of the group members shared:

There was a sick patient who was abandoned by family members. I knew how it felt because I had also been abandoned before until someone came to help me. So, I went to this house and found the place was smelly. The patient was in bed, which she had soiled with urine, vomit, and diarrhoea. I called someone else and we washed her, cleaned her beddings, and took her to the health facility for treatment. We enrolled her in a group so that she could get some food and psychosocial support. She ate and took her medication. Meanwhile, the home-based programme paid us allowances for the services we offered to other HIV people.

Another one added: ‘Some people came to the group looking very sick and weak that you just feel sorry for them. You cannot think about psychosocial support for such a person but to give food first and when they get stronger they can listen to matters related to HIV treatment, prevention, and education’.

They also observed that in Kibera, *msaada* motivated people with HIV and AIDS to participate support groups in large numbers. Another member of Kwa DO support group said:

With material support everyone went to those groups. ... Particularly cash money and foodstuffs attracted people to groups. ... People like free things, so when you present yourself as HIV positive people know you are sick and therefore weak that you cannot look for casual jobs.

In resurrecting lives, food and HIV treatment were inseparable. People were facing an imminent death, and most of them had no income. I contend that in the Kibera context, where poverty, unemployment, physical incapacitation, and abandonment were common, *msaada* was a survival strategy. I argue that material support was as necessary as psychosocial

reprieve, and that support groups were survival spaces. For people with AIDS, food was more important than psychosocial or informational support. The KIPOTEC chairman sums it up:

Support groups were very helpful. I personally benefited from them. Otherwise I would be dead by now. I was abandoned while very sick. I had no food and no one to care for me. I had lost hope. But people infected with HIV came and washed me, gave me food, and encouraged me to go for ARVs. They came every day to cook, clean me, and make sure I took my medicine. When I got better I joined them and also participated in home-based activities to help others.

The relationship between ARVs and food, as recommended in the Kenyan National Guidelines on Nutrition and HIV/AIDS (NASOP, 2007, 2008) that put nutrition as an important factor in HIV management and ARV effectiveness, and that was reinforced in treatment counselling sessions and support groups in the notion of positive living made material support equally essential in HIV treatment.

Beyond HIV crisis: New strategies, new populations

With the drying up of HIV funding following the global economic crisis, donors demanded a move to evidence-based strategies, especially when the prevalence rate was at 5.6 per cent. The 2009 Kenya HIV Prevention Response and Modes of Transmission epidemiological study (NACC, 2009) propagated new terminologies and categories of vulnerable communities, the ‘key populations’. Ragi rhetorically asked: ‘Was “MSM” something new? No, they have always been there, it has been practiced for a long time but there was no HIV intervention targeting them’. Mutongi (2012) shows that homosexuality has existed in Kenya for a long time. However, epidemiological data resulted in the ‘making up people’ (Hacking, 1986; Lorway & Khan, 2014). It created an ‘epidemiological citizens’ (Lorway, 2013) with high HIV prevalence, which led to new perspectives on HIV intervention strategies. Ragi explained: ‘New terminologies have come up such as demand-driven models, value for money, greater efficiency, effective partnerships, vulnerability³³ and risk, results-based,³⁴

³³ ‘Vulnerability’ refers to the probability that an individual (or group) is in a situation or practices behaviour that exposes them to HIV. ‘Risk’ refers to the probability of becoming infected because of a type of behaviour or a situation. (NACC,2009)

³⁴ ‘Result-based management: This is a programming approach focusing on ‘results’, defined as ‘a measurable or describable change resulting from a cause and effect relationship’. The change is a measurable transformation in an individual, a group, an organization, a society or a country.’ (NACC, 2009).

strategic investments, and understanding of the epidemic. You do not have choice; you put money where the epidemic is’.

Donors who were concerned with halting new infections and increasing access to HIV treatment desired that interventions be rights-based, cost-effective,³⁵ and accountable. As such, changes to strengthen HIV preventions were adopted. In responding to donors’ demands, attention and funding were redirected to ‘key populations’ who include men who have sex with men (MSM), men in prison, sex workers, and drug addicts (UNAIDS, 2010). At the same time, MSM and sex workers engaged in debates albeit with resistance from religious, political leaders, and the larger community. But they pressed on and, together with their supporters, began to make public demands for health and human rights through protests as well as dialogue. Policies such as the Kenya National AIDS Strategic Plan (KNASP) 2008/9–2012/3 were reviewed and aligned to the Paris Principles for aid effectiveness (NACC, 2009). The new terminologies mentioned by Mr. Ragi were at the heart of KNASP 2008/9-2012/3. The KNASP 2008/9-2012/3 proposed to reduce risky behaviours among the general public, the infected, and the most-at-risk and vulnerable populations. HIV prevention and funding was directed towards MSM and sex workers’ activities, focusing on access to HIV services and prevention of HIV through targeted structural and behavioural change interventions. As I show in chapter 7, the interventions provided MSM sex workers space to mobilize into a support group.

With the tilting tides of HIV funding, one would assume the groups that depended so much on donor funding would fold up. That is partially true. But in my fieldwork, begun in 2009, I found certain a few PLHIV organizations and support groups were resilient: while some folded up and a majority became dormant. A resilient few innovated in order to continue attracting donor funding. In addition, more groups continued to be formed following treatment literacy by MSF Belgium and HAKI. The KNH, groups increased based on emergent issues and were hyper- medicalized while the PLHIV-led community-based organizations and NGOs exhibited both resilience and redundancy.

³⁵ ‘The standard measure of cost-effectiveness in HIV prevention is the number of new infections prevented for a given amount of money spent. The more cost-effective the intervention the more cases of prevented HIV one can ‘buy’ with the available money in comparison with other interventions.’ (NACC, 2009).

New strategies and support groups in Kibera

The hype of support groups drastically dropped following the reduction in material gains. Furthermore, as I noted in chapter 1, out of the 78 groups in Kibera funded by NACC's Total War against AIDS (TOWA), only 8 were PLHIV related. A key informant representing PEPFAR stated that HIV support groups that claimed to provide 'social support' often went beyond a focus on HIV when they engaged in income-generating activities. A good number transformed into income-generating activity groups, mainly table banking (group savings and loans), merry-go-round, bead making, among other things. New support groups continued to be formed but they had a slow momentum or quickly became dormant. Every fortnight MSF Belgium and HAKI separately offered treatment literacy to newly enrolled ARV clients and after each training new groups were formed (see chapter 1). Family members were expected to do more in caring and supporting PLHIV (see chapter 5). Support group continued to be formed but they had a slow momentum or quickly became dormant. Support group memberships provided agency to demand for material support when it appeared. PLHIV city-hopped to KNH groups for psychosocial and HIV information, and to other support groups in the neighbourhood for material support.

Hyper-medicalization of support groups at KNH

'Without a support group you have no life', was a common statement expressed by members in KNH support groups. In many writings, an HIV-positive diagnosis is presented as a traumatic experience with negative implications on individual well-being including resistance to adopting coping strategies (Kyakuwa, 2009; Mello et al., 2009; Zhou, 2007; Chippindale & French, 2001; Burgoyne & Saunders, 2000). Reducing psychological distress and gaining emotional support is critical in discarding negative thoughts, thereby allowing one to alter thought patterns and behaviours and adopt coping strategies (Visser et al., 2005; Heyer et al., 2010). Through the promotion of 'living positively' messages, support groups were significant spaces for reinforcing coping strategies, treatment adherence and HIV prevention

Psychosocial, HIV information and communicating living positively were main components of KNH support groups. The main purpose of these components was to promote treatment adherence and prevention of HIV. Accepting and 'owning' one's HIV-positive status were focus for treatment adherence (Moyer et al., 2013). Acceptance of one's HIV-

positive status and change of identity was not a one-time event but a process. In KNH support group sessions, the acceptance of HIV-positive results and HIV-positive identity could be read from the opening prayer to introductions, to the sharing of experiences through to the HIV-information segment. The opening serenity prayer posted on the walls of support group venues reinforced acceptance. The prayer reads, ‘God, grant me the serenity to accept the things I cannot change, the courage to change the things I can, and the wisdom to know the difference’. A peer mentor unpacked the prayer to me as follows: ‘HIV positive status cannot change, but one can accept it and find strategies to cope. Challenges [lack of food, stigma] or behaviours [substance and alcohol abuse, risky sexual behaviours] are changeable – one can find ways to survive’. Therefore, group members were called upon to accept that the HIV-positive status could not be changed, and that it was important to accept it and take up their new identity. Doing so had the potential to drive positive decisions in adopting coping skills and cultivating a responsible HIV community.

Introductions were the next step in reinforcing acceptance. Peer mentors often argued that ‘the more a HIV-positive status is verbally professed the more it becomes owned and accepted’. During introductions each person stated their name, HIV status, day or year of diagnosis, treatment regimen, CD4 count, and next clinic appointment date. The peer mentors’ leader also argued that, ‘it is when people take up ownership of their status that they are able to make positive decisions’. Failure to confess verbally one’s HIV-positive status was seen as a state of denial and therefore non-commitment to coping strategies including treatment and prevention responsibilities. ‘*Kikombe cha Babu*’ (resorting to peculiar options) was made reference to when HIV status was not verbally declared in a person’s introduction. It was noted that PLHIV who did not accept their HIV were likely to subvert positive-living messaging by, for example, abandoning ARVs for alternative treatment, such as seeking out Ambilikile Mwasapile, a Tanzania-based traditional medicine man in Loliondo. Those reporting a drop in CD4 count were tasked to explain possible causes and were given advice on what to do to increase their CD4 count. Acceptance and adoption of coping skills were also reinforced through the sharing of experiences. This was beneficial in three ways: it helped members learn from each other, it brought about psychological reprieve, and it motivated people to adopt coping skills including treatment adherence. People shared negative thoughts, difficulties in accepting HIV status and adopting coping strategies, experiences with stigma, experiences with infant feeding, side effects of ARVs, experiences

of disclosure, practical needs, and lonely in their families, which impacted negatively on adopting coping skills.

For instance, a soft-spoken and smartly dressed 23-year-old Jamal, the sharing of his experience was usually limited to his name, status and a smile. When asked to say more about his family;

I am Jamal and HIV positive. It is difficult to be the only HIV positive person in the family. I lost my parents when I was very young. I was taken in by my uncle and aunt. They have three children. Then I began to be sickly when I was nine years old. My uncle gave me medication every day. When I was thirteen I got tired of the medication and refused to take it. My uncle brought me here (KNH CCC) and asked the nurse to talk to me about my health. I was told I was HIV-positive. My uncle said I was infected by my mother. I never tell people about my story. It is very painful to be the only one living with HIV in the family... I always look forward to this day (the day for the support group session). We are in this journey together. I feel much supported by the group when I hear various experiences. I have made friends in this group. We encourage each other to continue with medications. I feel encouraged.

Seventeen-year-old Sally, who accidentally learnt about her HIV-positive status while admitted in KNH medical ward, was very angry with her sister and the doctor for keeping it a secret from her. She refused to take ARVs. The KNH youth group peer mentor met Sally in the KNH ward and invited her to the KNH youth support group. One day, Sally was wheeled into the KNH youth support group. In ritualized introductions, the peer mentor strategically asked group members to reintroduce themselves and share their experiences with HIV diagnosis and living with HIV. After the rest of the group were through, Sally beamed with a smile said, 'You mean all of you are HIV positive! You look ok! You are smiling, you do not look sad! I thought I was alone, I felt so bad when I got to know about my status and did not want to talk to anyone'. She immediately started HIV treatment and her health tremendously improved.

Similarly, 33-year-old Marto, a KNH HIV peer mentor, often shared his life experience with HIV in support groups. He often began by saying, 'Without support group you have no life. Participating in it has totally changed my life'. He told them how he was involved in a terrible accident that led him to know he was HIV positive. He narrated his devastation when he learnt he was HIV positive, and how his life changed when he heard a pastor saying that he had lived with HIV for 20 years:

I was in a support group. I listened to people sharing and I was amazed at how long people had lived with HIV – some 10, others 15 years. The one who really touched was a pastor who had lived with HIV for 20 years, and he shared with the group the challenges, stigma and his determination. This gave me life.

Therefore, just meeting or being in contact with other people living with HIV and listening to them can go a long way in reversing hopelessness and despair, and resulted in psychological reprieve, acceptance, and adoption of coping skills (Heyer et al., 2010; Liamputtong et al., 2009; Visser et al., 2005; Kalichman et al., 2006; T. Nguyen et al., 2009; Van Deventer, 2000; Jackson, 2000).

The medicalization of HIV support groups was also reinforced through HIV information to create informed and responsible members. Using the CDC ‘prevention with the positives’ training manual, and peer mentors’ knowledge from MSF treatment literacy sessions, sessions covered basic facts about HIV, transmission modes, HIV progression, HIV prevention (condom use, PMTCT, family planning), and HIV management (ARVs, clinical care, CD4 count, nutrition and management of opportunistic infections). In many presentations, KNH HIV support group members, including health care workers, recognized the significance of HIV information in mitigating psychological stress, and impacting positively on treatment adherence, increasing access and utilization of health care services, and adopting other coping strategies. Some members shared in group sessions how a lack of HIV information led them to non-adherence and some to second-line treatment.

Cynthia, thirty-five-year-old middle-class nurse working at KNH shared in the KNH health workers support group that after suspecting she could be HIV positive, following bouts of illnesses, she travelled to Eldoret town (about 350 kilometres away from Nairobi), for an HIV test. She said: ‘There was a lot of stigma among health providers and I did not want anyone to know that I was going to take HIV test’. She tested positive and came back to Nairobi to continue with her work. Meanwhile, she sought treatment from Nairobi Hospital, a high-end private-for-profit health facility. The doctor gave her various options but she insisted on the best medicine. She opted for the most expensive, a second-line treatment, which cost KES 8,000 (80 Euros) per month. It later became more expensive. She transferred to a middle-income hospital, which was slightly cheaper, but again treatment became expensive. She remembered, ‘In addition my lower jaw got twisted and has affected my speech. I had heard about this group but it was difficult for me to join. But since I joined I have learnt a lot. I wish I had joined earlier; I would not be on second line. I have now

become knowledgeable about HIV treatment'. Like Cynthia, a majority of KNH health workers' support group members were on second line ARV treatment. This was blamed on the lack of information on HIV treatment.

When I tested HIV positive the doctor just gave me ARVs and told me to take them. He just told to take them. He did not give me any information. I think they (doctors) assume if you are a nurse then you are knowledgeable. I had no information. I took ARVs like the other drugs; only take them as long as I am not feeling well and stop when I feel better. That is how I ended up on second line because first line failed due to non-adherence (KNH healthcare worker's group member).

A peer mentor also shared how a lack of information can inhibit access to HIV treatment. He told how a 65-year-old woman used to travel all the way from Mombasa to Nairobi to attend HIV clinics and a KNH support group. The woman lost her husband 10 years before she got ill and was found to be HIV positive. Not knowing that her husband succumbed to AIDS-related illness, her lack of knowledge about HIV prevented her from understanding how she got infected with HIV in absence of her husband. At first she refused to take ARVs for fear of accidental disclosure to her children who would suspect her of immorality. However, when she learnt about HIV progression through the KNH support group, it became clear to her she was infected by her husband. She gained courage, disclosed her status, and enrolled for HIV treatment in Mombasa. Like her, through the HIV information shared in support groups, members reported discarding negative thoughts, enhance treatment adherence, prevent new infections, and adopt coping skills.

However, the groups carried both benefits and setbacks. Sometimes the groups that were potentially beneficial turned against some members. Most contentious issues were sexual and reproduction/PMTCT issues, survival and information.

Medicalization and sexual and reproduction issues

KNH support groups basically promoted what Mattes (2012, p. 75) calls 'pharmaceutical selves' in which patients' moral world concerns are often overlooked. HIV treatment or the management of HIV chronicity is more than drug intake. Being HIV positive, noted Ragi, 'it is not just the ARVs, PLHIV on ARVs have to enjoy life with ARVs'. The study by Burchardt (2009) show counselling sessions were 'the production sites of medicalized identities in which the medical meaning and practical requirements of living on HIV-treatment were systematically organized into the daily routine of chronically ill persons' (p.

335). The same holds for KNH support groups. Group were turned into HIV treatment adherence and preventive campaigns.

KNH support groups hyper-medicalized issues around sexual and reproductive lives. For women this was likely to interfere with reproductive autonomy, while, as I show in chapter 6 – a case study of an exclusive male sex therapy – there were efforts through medicalization to enhance male sexual prowess and reproduction. In KNH support groups, biomedical information on PMTCT or reproduction included maintaining a CD4 count above 500, a low viral load, disclosing to partner, family planning and sperm washing, taking ARVs, and infant feeding.

The antenatal PMTCT support group was well attended, attracting between 15-20 members per group meeting. A majority were women. They met from 11.00am to 1.00pm in a spacious room at KNH's clinic 18. On 18 April, 2012 group attendance was at 23 (20 women and 3 men). On this particular day a group of eleven health providers (nurses and nutritionists) and a peer mentor were in attendance. One by one, group members introduced themselves and share their experiences with HIV. In emotionally charged atmosphere, members narrated experience with HIV- positive diagnosis and experience with stigma. Some came to know their HIV status after multiple death of children or miscarriages, and a few following partners' concomitant illnesses. Those with HIV – positive partners blamed the infection on the partners. Those in discordant relationships (HIV-positive with HIV- negative partners) blamed the infection on blood transfusion during miscarriage. A few in discordant relationships reported suicide attempt despite having supportive partners.

The women openly vented anger, frustrations, fears and concerns, and received emotional support from their peers (Visser et al., 2005; Johnson, 2003; Heyer et al., 2010). Their narratives could be summed up in five words: guilt, anger, betrayal, despair and desire. They were angry because they were innocently infected, feelings of betrayal, and guilt for bearing the responsibility for acquiring HIV. They desired love and moral support. However, after the last member shared, one of the nurse counsellors said:

The fact that you are HIV- positive and pregnant means you had sex without protection, and you did not come with your partner to clinic for advice from the health workers, it is likely most of you did not disclose, and therefore everyone exposed their partner to a HIV infection. This statement deflated the group members who remained quiet for rest of the session as the nurses and nutrition counsellors did most of the talking. This marked the death of the support group. None of these members showed-up in the next group meeting. Only two new women

and five health-care workers turned up. I (researcher) was the only one who showed-up for the third and fourth meetings. Three weeks later I met one of the group members who told me the group was a stress. 'We are told to share, which we do but the nurses use the information against us. How can we be accused of exposing our husbands to HIV infection? Not all of us do it intentionally. As a woman when you are HIV-positive am stressed, and I come to the group for support. ...That was an insult. And if that is what we get from support groups, I would rather keep off. It is my right to have children. The nurses are to advice on how to get HIV- free children period.' Health providers used HIV technological advances and biomedical information to entice group member into approved lifestyles to prevent HIV infection and promote treatment adherence.

In the discordant couple group to get pregnant, the nurse counsellor insisted on three conditions for reproduction to take place: a CD4 count from- 500 and above for a HIV-positive partner, a sperm wash, and disclosure to partners. To pursue their reproductive autonomy and desires, a peer mentor shared how some women once achieved a CD4 count of 500 and above, and then dropped out of support groups to avoid pressure to conform the rest of the advice to sperm wash, engage in family planning, and disclose to her partner, and to avoid being accused of putting her partners at risk. During walking sessions they shared tips on how to get babies without being subjected to sperm wash. 'Nurse Counsellors get knowledge from reading books but we speak from experience' (KNH support group member). While the nurses pushed for the biomedical agenda, the women subtly pushed for recognition of their autonomy.

Medicalization of support groups and morality of survival

Treatment adherence (taking treatment at a particular time) was meticulously promoted for better health outcomes in KNH support groups. Little or no attention was paid to the economic, social, and cultural struggles that group members faced. The KNH HIV program provided fortified flour to only undernourished HIV positive clients for a limited period of three month. In support groups, some members including some peer mentors shared about the lack of urgent practical needs especially food.

One day, Martha, a peer mentor, and I were at a KNH patient support group for a group session. Five minutes after the start time, a nurse counsellor who co-facilitated the group session came in to find that there was no quorum yet. Martha engaged the nurse counsellor in a discussion on empowerment of support group members, asking the nurse, 'Do

support groups really empower members?’ ‘Very much’, responded the nurse counsellor. Martha shook her head in disagreement and went on to express her opinion:

How can you say support groups empower people and all we do is to give information? A woman comes to support group and shares that her husband has beaten her after disclosure, and we just offer her advice without solving the real problem. She is going back to the same man who might beat her and chase her away. Did we empower this woman? Others come to the group and share about lack of food and job, and have children. All we do is empathize with them as they go back home hungry, no food for the children, yet we have taught them about treatment adherence and nutrition, stressing balanced diet. We even caution them about their CD4 not doing well, like reduce stress, eat well. In that case, have we really empowered them? Many people come with various challenges and we empathize telling them ‘tumesimama na wewe’ (we stand with you) or ‘tuko pamoja’ (we are together in this), take tea and snacks, and they go away just as they came, perhaps with more misery because their expectations having not been met. Failing to give material assistance or intervening in gender-based violence is not empowering group members.

‘*We stand with you*’ or ‘*we are together in this*’ communicated care and support in KNH support groups. As noted above, the significance of nutrition in HIV, especially the interaction with ART has been noted (NASCOP, 2006, 2008; NASCOP & USAID, 2007; WHO 2003, 2004; Hardon et al., 2007). Food and other essential needs remain a challenge for PLHIV on ARVs in low-resource setting (Le Marcis, 2012; Marsland, 2012; Prince, 2012; Kalofonos, 2010). The support group was promoting living-positive message, some group members including peer mentors were struggling with issues such as food, or poverty, disclosure dilemmas that could have a negative impact on the coping strategies. Some peer mentors, in addition to lack of food, they walked to work in KNH, and others were locked out of their houses for failing to pay rent. Martha pointing out put the struggles some group members face that trouble empowerment role of support groups.

Resilience and redundancy of community-based institutions and skills

The dwindling funding affected HIV activists/experts, PLHIV-led NGOs and CBOs and HIV support groups in different ways. Some NGOs, CBOs and support groups continued to exist by being creative and innovative. The local NGOs, mainly mogul organizations, though

focused on mobilizing people living with HIV in support groups as a primary activity, took on other activities to remain relevant to HIV funding. Three of the HIV moguls' NGOs transitioned from being receivers to providers of services, becoming the interface of a community-based approach and a clinic-based approach. KENWA and KICOSHEP established home-based care rescue centres, a 'home from home' facility model. In this model, in-patient PLHIV were those who were incapacitated due to AIDS-related illnesses and who lacked familial social support.

The Women Fighting AIDS in Kenya (WOFAK), established a health facility running full-fledged testing and curative services in Kayole.³⁶ Psychosocial support sessions and home-based care services in the community were also provided. The Movement of Men against AIDS in Kenya (MMAK) focused on 'positive masculinities' while TAPWAK and the Foundation of PLWA in Kenya (FOPHAK) focused on creating more support groups in communities and organizing other activities in Nairobi's informal settlements and rural communities, respectively. HAKI, a CBO in Kibera, adopted a business model. It offered loans and a savings facility to PLHIV and other people in Kibera. At the time of the study, HAKI CBO was overseeing over 50 savings and loans groups through which more than four million Kenya shillings was circulating in Kibera (see chapter 5).

The reduction in HIV funding, however, did not abate misappropriation of the funds that were still available. After attending a KNH adult support group one Saturday, I joined some friends at a church service. During the time for testimonies, one lady spoke up:

I'm HIV positive [some church attendees sighed and she told them not to feel sorry for her]. When I came here I was very devastated. I have a support group for women who are HIV positive. I support them with foodstuffs. However, I got this boyfriend and spent KES 5 million (equivalent 50000 euros) on him. The money was meant for women's food in my support group. This man left me when the money got finished. But God was faithful, the women never went hungry. I just got another donor who has funded the group to a tune of KES 5 million.

With HIV funding shortfalls, the existence of organisations and groups, and HIV activists/experts that were mainly donor dependant was threatened. PLHIV-led organizations that did not adapt to changes ended up closing down. For instance, a 38-year-old John, who once ran a successfully funded CBO and lived in a middle-income area, is now 'redundant'.

³⁶ This is the place where WOFAK established the first food basket programme.

Not being able to secure funding, John's CBO closed and he was not hired anywhere else. Like John's organization, most CBOs that did not have a sustainability strategy had to shut down operations. Similarly, support groups were affected. Most groups became dormant and only restored during the rare advocacy activities or responding to call for proposals by NACC. However, a noted above very few were funded by NACC. Patient experts/activists were affected; labour was lost and acquired skills/expertise became redundant. Some of the activists abandoned HIV to venture into non HIV fields. Unlike Joseph (introduction) who had an established career to fall back to, John, who had no formal training other than HIV activism, did not find a job. I met one of the founders, and first chief executive officer (CEO) of the National Empowerment Network of People living with HIV/AIDS in Kenya (NEPHAK), the largest PHIV network, and on asking her about what she was up to since she left NEPHAK, she responded, 'I am not going to live on HIV alone for the rest of my life. I am doing other things for a living. Some people don't have anything else to do other than live on HIV. I have made my mark in HIV interventions in Kenya, and now I have ventured in other non HIV fields. I am running an NGO for women that focus agriculture in Western Kenya'. After NEPHAK, and failing to secure more opportunities in HIV world, this former CEO moved on to venture in other fields. HIV interventions have buried skills (especially peer education/counselling and embodied individualised experiences) and knowledge.

Conclusion

This chapter describes the local and global response, specifically HIV treatment and funding, in the history of HIV support groups. External and internal factors contributed to rise, proliferation and the fall of support groups: moral discourses, stigma, economic insecurity, and weakened social support were the key internal factors, while massive funding or HIV aid, HIV technologies, global policies, and donor agendas are among the external factors. I have shown an intersection of HIV treatment, funding, PLHIV needs, and the proliferation of 'NGO-zation' and support groups. I have also shown how biosocial relations are shaped by epidemiological findings, human rights advocacy and funding, and the role of funding in the diversity of groups.

HIV funding, better known as *msaada*, coupled with HIV treatment, resurrected lives. While they competed for resources, NGOs and support groups played a key role in distribution of *msaada*, providing home-based care services and income opportunities,

without which lives of people with HIV and AIDS would have been worse. Similarly, information played a significant role in coping with HIV and even resurrecting lives. While PLHIV in low-income areas may seem to have displayed a yearning for *msaada*, overshadowing the psychosocial usefulness of these groups, I argue that practical needs were equally as important as psychosocial support.

In this chapter I have also shown intensified medicalization of KNH support group space is both advantageous and disadvantageous. It improves knowledge and coping with HIV while at the same time it brings about anxiety and interferes with autonomy or freedom of choice.

I have shown narratives of redundancy, and resilience of NGOs, CBOs, support groups and patient experts/activists after HIV crisis. Based on the expansion of KNH support groups, despite the dwindling funding, I hypothesize that without a cure for HIV these groups will not disappear. They remain an important platform for psychosocial and informational logics of care and support for PLHIV. In the community, as long as people continue to be initiated on ARVs, support groups will continue to be formed. However, their viability is very much dependent on the ingenuity of the leaders.

CHAPTER 5
WHEN FAMILIES FAIL: SHIFTING EXPECTATIONS OF CARE
AMONG PEOPLE LIVING WITH HIV IN NAIROBI, KENYA

Published as: Eileen Moyer and Emmy Kageha Igonya. (2014). When families fail: shifting expectations of care among people living with HIV in Nairobi, Kenya. *Anthropology & Medicine* 21 (2) : 136-148. doi: 10.1080/13648470.2014.924298
<http://www.tandfonline.com/doi/abs/10.1080/13648470.2014.924298>. Both authors contributed equally to this article.

Abstract

The availability of free antiretroviral treatment in public health facilities since 2004 has contributed to the increasing biomedicalization of AIDS care in Kenya. This has been accompanied by a reduction of funding for community-based social care and support organizations since the 2008 global economic crisis and a consequent donor divestment in HIV in Africa. This article explores the ways that HIV interventions, including support groups, home-based care and antiretroviral treatments have shaped expectations and relations of care in the low-income area of Kibera in Nairobi, Kenya over the last decade. Findings are based on 20 months of ethnographic research on HIV care and support conducted in Nairobi between January 2011 and August 2013. By focusing on three eras of HIV treatment—pre-treatment, treatment scale-up, and post-crisis—the authors illustrate how family and community care have changed together with shifts in intervention funding. Many support groups that previously provided HIV care in Kibera, where the state is largely absent and family networks are thin, have been forced into hibernation. Mass HIV treatment programmes may allow the urban poor in Nairobi to survive, but they are unlikely to thrive. Many care needs continue to go unmet in the age of treatment, while many economically marginal people who had found work in care-oriented community-based organizations, now find themselves jobless or engaged in work not related to HIV.

Keywords: HIV/AIDS, care, community-based organizations, social support, Kenya

Introduction

On Wednesday, 12 May 2012, in Nairobi's notorious Kibera neighbourhood, eleven people gather for their first support group at HAKI, a community-based organization (CBO). These four women and seven men completed treatment literacy training the week before. Such trainings are meant to educate and empower those who have recently begun antiretroviral treatment. HAKI sponsored treatment literacy trainings for community members, usually sticking closely to a programme pioneered in Kibera by Médecins Sans Frontières (MSF Belgium) in 2002³⁷. Following a script that has become routine in HIV support groups worldwide, they shared experiences with HIV, including fears of death, experiences with stigma, difficulties with disclosure and with taking medication, and expectations and disappointments with social support. Twenty-seven-year-old Jacob's story was both typical and compelling:

When I came to Nairobi in 2003, I only knew my cousin who lived in Kibera. He took me in and when I got a job we decided to live together and share rent. We were casual workers in the Industrial Area and paid our wages weekly. We were very close...we lived together, socialized and enjoyed life...we did almost everything together. Things dramatically changed in 2011 when I started getting ill and could not work. As a casual worker you are paid when you work. This meant I did not have money. My cousin changed. He started not coming home on Fridays when he was paid and only came home when he had no money... he would disappear, abandoning me in the house for two or even three weeks. I suffered...I had no food and no one to care for me. I thought I would die.

Fortunately a neighbour heard about me and brought me food and water. My cousin came back one day and told this neighbour to raise bus fare to transport me back to my rural home. Instead, my neighbour—a married woman with children! —who is not my relative! —took me in. She told me I would die if I went home, but that she would take me to MSF for treatment and that, as long as I committed to taking medicines, I would live. I lived in her house for two months. She cleaned me, washed my clothes, gave me food and ensured I took

³⁷ MSF has worked in Kibera since 1998 and have been offering antiretroviral treatment and support since 2002. In April 2005, they launched a HIV comprehensive care center, jointly run by the ministry of health and they currently operate several other facilities in Kibera. 'In 2012... (they) provided anti-retroviral treatment to 4100 HIV patients in Kibera. Over the years, the organization has pioneered several innovative models of care, such as developing HIV patient support groups to boost adherence and empower patients.' (<http://www.msf.org/article/kenya-new-clinic-brings-comprehensive-care-most-vulnerable>, accessed 14.1.14).

my medicines. HAKI staff heard about my case; they visited, brought food and encouraged me.

My cousin never came to visit...I never heard from him during the time I lived with my neighbour...After two months my health improved greatly. I went back to where I lived with my cousin. He was shocked to see me. Since I was not strong enough to look for work, I told him that I should not go hungry...that he should buy me food. Still, he would disappear on Fridays and only come back when he did not have money. He even stopped paying rent. When I confronted him, he responded, 'Your HIV has made you so harsh...I am not the one who gave you HIV'.

Jacob's story points to several aspects characteristic of the last decade in Kenya, a country that has witnessed a rapid turnaround in regards to HIV/AIDS. Antiretroviral treatment has become widely available and, especially for those living in cities, the possibility of living a relatively healthy life after an HIV diagnosis has become imaginable. Simultaneously, however, access to reliable and ongoing care has become more challenging in the age of treatment, as resources to fight the disease are channelled into programmes that provide medication.

This article examines the ways HIV and the availability of HIV treatment have altered the terrain of care for people with HIV and AIDS in Kibera, one of the poorest neighbourhoods in Nairobi, Kenya. Care here is defined in relation to antiretroviral treatment, the biomedical response of choice routinely provided by both donors and the Kenyan state to people with HIV in Nairobi. Unlike biomedical treatments, which target the virus, HIV *care* encompasses the physical, emotional, social, and economic needs of people infected with HIV, which generally exceed the efficacy of biomedical treatment. Care thus defined—in Africa as elsewhere—is rarely offered by the state. Instead, care is something that is done by family, friends, occasionally the wider community, and increasingly the self. The act of caring is also often at the heart of what defines people as family, friends, and community. In the case of HIV, for many years in many places, such care has also been done by people working for (usually volunteering) non-governmental organizations (NGOs), including church groups, social support groups, and other community-based entities. Some, like burial societies and merry-go-round saving associations, emerged prior to HIV, offering means for people to unite under one umbrella to provide support in times of need. Others, like home based care (HBC) programmes, HIV support groups, and post-test clubs, emerged in response

to the care needs of people with AIDS that were not being met by existing and often overburdened social institutions, including the public health system and the family.

It is not unusual to hear stories such as Jacob's, in which family members disappear when they suspect or learn of a relative's HIV status to avoid offering care, economic or emotional support. Although, it is true that some do enjoy social support from family, others find that support is unavailable when needed most. Providing care and support to someone with HIV can be challenging for family members, especially when the person is extremely sick. It requires physically tending to individuals who may not be able to bathe or feed themselves, and reassuring them there is no shame in not being able to control one's bowels. As De Klerk (2011) has eloquently argued, there is a physicality to care that often goes unrecognized, requiring family members who may be old, undernourished, overworked or otherwise overburdened to lift, carry and clean loved ones (cf. Geissler & Prince, 2010). The task is also often emotionally taxing, demanding caretakers to stare death in the face, while providing support to a loved one who may have brought shame on the family (Dilger, 2006, 2008). It can also be financially devastating, especially if more than one family member is sick or if the sick family member has dependents requiring support.

Despite such challenges, many who experience HIV-related sickness or social challenges expect their families to care for them. Jacob expressed shock that a neighbour who was not his kin volunteered to care for him. Jacob believed it was his cousin's duty to care for him in absence of other family. Aside from familial duty, Jacob and his cousin had developed a close friendship, which Jacob expected would yield some benefit in a time of need. It was unsettling to him that the care he thought was his right should be denied.

Fortunately for Jacob, Kibera is densely populated, and there is little privacy, meaning neighbours know what goes on in each other's homes. It is typical that the person who cared for him was a woman and not unusual that she would have been somewhat knowledgeable about HIV and how to care for someone infected. Though Jacob did not report the woman's HIV status to us, as a resident of Kibera, chances are she had been personally touched by the disease in some way, had already provided care to someone in the past and felt it was her moral duty to care for the hapless Jacob, stepping in when his family failed him. In addition to this neighbourly support, Jacob received regular visits from HAKI's HBC team, which provided both emotional and material support in the form of food; he also received treatment from MSF. When Jacob's family failed him, members of the Kibera community, including neighbours and HAKI, stepped in, linking him to the nearby MSF facility where he could get

treatment and also providing sufficient emotional and material support for him to regain his health.

The right to care

Although family support can be extremely important for those coming to terms with an HIV diagnosis, like Jacob, they often end up being disappointed and, consequently, are quick to share such experiences in support group settings and with sympathetic researchers. The moral outrage Jacob expressed through his story about his family's failure to care was similar to many stories heard in many support groups in Nairobi. Underlying such stories is the assumption that the burden of care and support for the sick should fall on the immediate family and extended kin networks. Such stories work to perpetuate societal norms regarding the expectation of family care, while providing a means through which people with HIV can reassert their humanity and the right to be cared for by kin.

Anthropological research in many African settings has demonstrated that despite the commonality of such norms, families often do fall short, particularly when it comes to providing care for people with HIV.³⁸ Such failures are often moralized; in defence of not caring enough for those dying of AIDS in pre-treatment era Tanzania, family members in rural areas often blamed kin, especially urban migrants and women, for their sickness (Setel, 1999; Dilger, 2006, 2008), whereas Mattes' (2012) research showed that moral blame continued to justify poor care within families even in the context of treatment.

Whereas invoking morality to justify the failure to care *within families* has been well documented in the case of HIV in Africa and beyond, much less attention has been paid to the ways that people with HIV make moral claims upon the family to provide care. Both Moyer (2012) and de Klerk (2013) have demonstrated how failing to care and stigmatizing those with HIV has been figured as uncivilized and immoral in Zanzibar and Kagera, Tanzania respectively, and Moyer has demonstrated how HIV positive activists can 'flip' the discourse of blame to demand better care and challenge discrimination from family and community members. Although one might argue such claims can be traced to the emergence of activist identities in some contexts, the commonness of such claims among participants in this study, suggest that the phenomenon extends beyond the biosocial space of HIV activism and points

³⁸ For an excellent recent review of this literature, see Seeley (2014).

to shifts in the ways that HIV is being re-moralized within family contexts in Kenya more broadly in the age of treatment.

Writing prior to the emergence of HIV, Vaughan (1983) questioned anthropological and historical constructs of the family in Africa. The ‘African family,’ often idealized and moralized in informants’ normative accounts of everyday life, is easily reified by research that fails to attend to the ways that family relationships and transactions shift over time and across place. To understand the ways kinship and kinship expectations are defined in context, Vaughan suggests that researchers approach the subject ‘sideways’ and examine non-familiar relations. By examining family-based HIV care relations, or more specifically, the failure of those care relations, this article, attempts to provide some insight not only into the ways that care is being redefined and re-moralized in the context of HIV treatment, and perhaps also the ways that kin is redefined in the context of HIV care.

Methodology

This article draws on 20 months of ethnographic research on HIV care and support groups in Nairobi, Kenya, conducted between January 2011 and August 2012. Although research was conducted in diverse localities within the city, this paper focuses on data collected at Kenyatta National Hospital (henceforth Kenyatta) and in the informal neighbourhoods of Kibera. The research utilized ethnographic methods, including participant observation, interviewing, informal conversations, FGDs and ‘walking sessions’. Participant observation was conducted during support group sessions. Walking sessions were an organic continuation of the KNH hospital’s support group sessions and took place outside the support group setting when the first author walked with group members from the hospital to downtown Nairobi where they boarded their buses home. These sessions lasted approximately 45 minutes and focused on what had transpired in the support group, providing insight to members’ perceptions of the groups and background information about members, including their relations with family members. Some follow-up interviews and observations were conducted with group members in their homes. Numerous informal conversations were also held with support group members on the telephone.

Twenty-nine formal interviews were held with participants purposively sampled from support groups (eighteen from Kenyatta, eleven from Kibera). Six FGDs were conducted:

two with support group members from Kenyatta; two with HIV positive support group members in Kibera; and two with Kibera community members whose HIV status were either negative or unknown and had lived in Kibera prior to 1984, when the first HIV case was announced in Kenya. Interviews were conducted in Kiswahili or English.

Shifting configurations of care

The responses of families, as well as community and health facility-based support groups to HIV have been shaped by historically shifting conditions in Kenya, including new medical technologies, international aid, the national HIV response, and the extent to which rights and dignity have been ascribed to HIV positive individuals. Whereas antiretroviral treatment has dramatically reduced the care burden on one hand and helped to conceal it on the other, social technologies like support groups, treatment literacy training, and HIV activism have heightened PLHIV's expectations of care from the state, from their communities, and, importantly, from their families.

In Nairobi, shifting expectations of care have also taken place within a broader context of steady urbanization, growing inequality, the increasing nuclearisation of families, and a growing number of women in the workplace. Whereas this broader context has limited the extent to which urban households—particularly women struggling to balance work and family obligations on tight domestic budgets—could provide care for chronically ill family members, shifts in the way HIV has been framed by national, international, and local responses have contributed to the way that care in the home has been valued, both economically and morally.

In the early part of this century, when the Kenyan government began taking HIV seriously, the state, as well as international donors, recognized the need to strengthen care and social support for those infected with HIV. In the absence of reliable familial and kin-based care in the cities, a move was made to reorganize support away from families to community-based programmes through HBC and HIV support groups. Institutionalized social support, organized through NGOs and health facilities, became the norm in the era of treatment scale-up. Whereas HBC was key to this shift early on, as the positive effects of treatment began to be seen, the need for palliative care reduced drastically, and peer-to-peer support groups began filling gaps in social support (Brashers et al., 2004; Heyer et al., 2010).

Kibera, where most of the research for the article was conducted, is an ‘informal’ neighbourhood and does not officially exist in the policy world. As such, the Kenyan state does not provide public services, including health services, to the approximately one million people living there. Because Kibera is located within the city limits and is only five kilometres from the city centre and a short walk to both Kenyatta Hospital and Mbagathi District Hospital, however, residents have fairly easy access to some of the best public health care in Kenya. Additionally, Kibera’s health needs are served by a complex network of NGOs, the best of which—like MSF and HAKI—are physically based in Kibera. Although the hospitals are state-run, similar to many NGOs, they rely heavily on funding from international donors. The ‘NGO-zation’ of Kenya has affected all health services (Hearn, 1998), but the effect been most visible in the context of HIV-related health issues (Prince, 2012). Kibera offers an extreme case of NGO-ization, even by Kenyan standards. This has been driven by the lack of formal public services in the area, but has also likely resulted from the ease by which it is reached by the donor community and its relative safety compared to other neighbourhoods such as Kariobangi or Mathare. Although there are other low-income neighbourhoods in Nairobi, some of which are arguably poorer and less served, none have captured the world’s imagination to the extent that Kibera has, with its close proximity to downtown Nairobi and the regional headquarters of countless international NGOs.

Provisional responses in precarious contexts

Following Geissler’s (2014) imagination of public health landscapes in Africa, Kibera should be considered the ‘big island’ in Nairobi’s public health archipelago. With a few exceptions, the HIV services offered in Kibera have been patchwork and time-limited. For Kibera residents then, the provisional and precarious nature of HIV services mimic the provisionality and precarity of daily existence. In such environments it is common to witness ‘flexible configurations’ of what Simone has called ‘deterritorialized frameworks of social reproduction and political identity’ (2004, p. 5).

The CBO known as HAKI is one such configuration. HAKI was founded as a self-help, micro-finance group in 2002 by 25 individuals running petty businesses in Kibera to gain financing from the Kenya Rural Enterprise Program, but it has evolved over its 12 year history to meet the needs of its steadily growing membership, all the while relying on

minimal donor support. Early on, Charles Ogotu, the leader and brainchild of HAKI, linked high rates of loan defaulting to HIV, when five members who failed to repay loans died of HIV. Ogotu, who has known he is HIV positive since 2002, began living in Kibera in 1999 when he migrated from Nyanza with his wife. Under his business-like leadership, HAKI officially became a CBO in 2005 with the explicit aim of fostering economic empowerment among their HIV positive membership, as well as seeking ways to finance the organization's home-based care, legal aid, and orphan care programmes.

Although research for this article was conducted in multiple care-oriented organizations in Kibera, HAKI stood out for its success. At a time when many other organizations were collapsing due to lack of donor funding, HAKI remained a strong community presence. Like many other HIV-related organizations in Kibera, HAKI had blossomed during the early years of treatment scale-up (2004-2009) when donors favoured CBOs with generous grants to fill gaps in what was seen as an over-burdened health care system.

The remaining three sections of this article examine configurations of HIV care in Kibera in three eras: pre-treatment, treatment scale-up, and what we refer to as the wake of the crisis. This periodization approach provides insight into the way that care needs, expectations of who should provide care, and how those providing care should be compensated have shifted over time.

Care and support in the city prior to antiretroviral treatment

In focus group discussions about care and support before and during the early years of HIV, most agreed that care for the sick had been the responsibility of family and kin, and that families usually managed to meet their obligations. Although such sentiments were most likely shaped by idealization of the past and conflations with rural norms, there were enough detailed examples of good care that had been provided by kin in Nairobi to argue that the coming of AIDS made it difficult for families to fulfil care obligations for a range of material, moral and emotional reasons.

Even before HIV, however, prolonged care for the sick in urban homes was expensive and presented challenges, putting a strain on kin networks (Iliffe, 2006). In urban homes, most family members either worked or were actively seeking work, meaning an outsider had

to be assigned care tasks: feeding the patient, ensuring medicines were taken, accompanying the patient on follow-up visits to the hospital. However, unlike family-based care, which was presumed to be obligatory, even if mutually so, care provided by outsiders was considered a debt (Seeley, 2014). Neighbours helped one another with the expectation of later reciprocity; others expected to be paid. Outsider help also had its limits. People we interviewed agreed that there were many intimate tasks you could not ask neighbours to perform and, further, that neighbours were to be called upon for temporary crises such as funerals and acute sickness, not for long-term care.

Given the limited extent to which urban residents could offer or expect family-based care, it was not uncommon for people to rely on rural based health facilities and extended families for *care and support in times of prolonged illnesses*. Even in the present, urban dwellers report an important reason to maintain links with rural relatives is the care they are likely to provide for urban kin with prolonged illnesses. Interviewees reported that rural hospitals were cheaper and using them made it more convenient to involve rural kin in long-term care, allowing urban dwellers to provide monetary and emotional support. Relatives also routinely sent urban kin to rural areas when they were suspected to be suffering from a condition best treated by traditional medicines, or to save the cost of transporting a body home for burial when death seemed eminent.

Caring for any sick relative with a prolonged illness is difficult in Nairobi, but caring for relatives with HIV presents additional challenges. If left untreated, HIV leads to a painful, messy death, and requires around the clock nursing. Prior to the availability of treatment, people in Nairobi abandoned bedridden relatives in their homes or at health facilities like Kenyatta. The breakdown in family care and support can partly be explained by the care burden the disease brought, however, many participants observed that faltering social support in the face of HIV was due to ignorance and fear:

Before they knew what the cause of the disease was, they were very concerned and would look after the person and try to find out what was the problem. But when it was discovered you were HIV positive, they knew you were dying, no treatment, they just abandoned you or took you to rural home to die there. (FGD, HIV positive woman)

The truth is there was a time when people were very sick; they had prolonged diarrhoea till they were finished. People were very scared of them, feared them; family members would abandon them and neighbours just came to look at them from afar, they would not touch them. It took a Good Samaritan to tend them; sometimes they used to die in the houses.

(FGD, HIV negative woman)

As the burden of HIV grew and more families failed to cope, care and support began to be offered to the bedridden though HBC services provided by local churches, NGOs and CBOs:

There were those (sick people) who were alone in the houses... We had some people from the Catholic Church who used to come to bathe them, clean their houses and wash their clothes, cook for and feed them, even cook for the children, and give them medicines. (FGD, HIV positive woman)

Similar to what Simbaya and Moyer (2013) have argued for Zambia, community-based responses during the pre-treatment era in Kenya were often motivated by pragmatism, a sense of charity and moral obligation. In Kenya, most who provided care and support through HBC programmes in the pre-treatment days did so for little or no remuneration and received little training. It was only in the era of HIV treatment scale-up—and the accompanying scale-up of international aid—that community based care and support began to receive considerable sponsorship from international donors (Wringe et al., 2010).

Care and support in the age antiretroviral treatment and msaada

Similar to other countries in Africa, free antiretroviral treatment first began to be provided in public health facilities in 2003 in Kenya. By 2004, programmes were expanding rapidly, and those most in need found it relatively easy to access treatment in Kibera. At the time, public health experts were concerned about adherence, worrying that without proper support, people would fail to take their medicines as prescribed, inviting treatment failure and viral mutations that would defeat the available medications. Defining and delivering adequate social support to those on treatment became a key objective of state-coordinated treatment programmes and the donors investing in treatment.

There was agreement that patients should receive adherence counselling and that those from lower socioeconomic backgrounds would require material support to ensure adequate nutrition. Whereas the upper and middle classes of Nairobi, who often accessed treatment in private health facilities, received basic and usually one-off adherence counselling, those who attended public facilities like Kenyatta were subjected to rounds of adherence counselling and strongly encouraged to join one of the hospital's health worker

facilitated support groups (Mattes, 2011). Those who sought treatment at the Kibera-based MSF programme benefitted from a week-long treatment literacy training, based on models developed by treatment activists living in Western countries, to provide PLHIV with extensive information about their disease, treatment and what was called, ‘living positively’, a package of lifestyle advice designed to deliver optimal health through eating well, exercising, avoiding alcohol, tobacco and other intoxicants, and practicing safe sex. As with Kenyatta, MSF clients were also encouraged to join support groups.

Following the MSF model, many CBOs in Kibera began sponsoring support groups for the people living in their immediate environs.³⁹ In this way, small NGOs and CBOs in Kibera emerged as key players in treatment scale-up, offering spaces where those recently initiated on treatment could gather to share their experiences and garner emotional support; but also—and importantly—they became a means through which much needed material support could be delivered to ‘the largest slum in Kenya’. The relationship between international aid organizations and Kibera-based NGOs and CBOs benefitted both sides; whereas the donors were in need of a public to help and suitable partners to deliver their product, the NGOs and CBOs needed capital to operate and expand.

According to study participants from Kibera, the coinciding of free treatment with material support reinforced beliefs that CBOs and health facilities, rather than families, should serve as the most important source of social support. In many ways, the very word ‘support’ came to be equated with material rather than emotional support during this period in Kibera, and most-often was translated in Kiswahili as *msaada*, literally meaning help or assistance, usually of the material kind.

People came to help us in Kibera. They brought *msaada*...food, school uniforms, school fees, money for shopping and rent...this *msaada* really helped people who were bedridden to recover. (FGD, HIV positive woman)

People sick from HIV and their families looked to NGOs and CBOs for care and practical needs. When HBC helpers arrived in homes, family members would show them to their bedridden relative, often with the phrase: ‘Here is *your* person’. One PLHIV who worked as a home-based caregiver during that period recalled:

Those bedridden were locked up while family members went to work, or they just refused to offer them nursing care... I went to some houses and found the bedridden patient was locked

³⁹ Initially, MSF offered treatment literacy training and support group services to anyone on treatment, but now their groups are only open to people receiving treatment in their facilities.

in from the outside... had not been washed, had soiled his beddings and vomited on the floor... Houses used to stink... We used to wash them and clean them. Some NGOs came and would pay us, but we also felt it was our responsibility to do that because most of us had recently been resurrected because of the care we received from other people infected with HIV. Our own family members feared touching us, so if no one came to your assistance you would stay in soiled linen.

People who survived long enough to receive treatment when it became widely available in 2004 commonly used words like resurrected or revived, but they were just as likely to attribute their salvation to the care given to them by fellow PLHIV working for CBOs as they were to antiretroviral medicines. John, who lived in Kibera at the time, insisted that HBC services revived him. He had been a police officer living with his wife and children. When his health began to fail, he lost his job, and his wife left him. PLHIV working as HBC providers found him, took him for treatment and then visited him daily, washing him, cooking for and feeding him, all the while encouraging him until he 'revived,' at which point he felt morally compelled to join the HBC providers.

There is no doubt that the coming of antiretroviral treatment saved the lives of many in Kibera, as well as alleviating the need for palliative care. It did not, however, erase people's need for care and material support as they recovered; nor did it compel relatives to assist HIV positive people with basic needs while they struggled to regain their health. Especially for the urban poor, HBC and other activities sponsored by CBOs were a vital component of early treatment initiatives, addressing gaping holes in kin-based care networks.

Care and support needs in the wake of crisis

Around 2009, the crisis mentality that surrounded HIV began to level off in Kenya, as well as among international donors, many of which had to reduce expenditures following the 2008 economic crisis. Although people were still dying, treatment was available in public health facilities, and HIV-related morbidity and mortality had drastically reduced. Despite widespread divestment, generally speaking money for medicines continued in the wake of the global economic crisis. Much of the money that had been available for HBC and support groups was linked to international funding initiatives that came to an end. This meant that NGOs and CBOs, which had flourished during the treatment scale-up era because they were

able to provide services and goods, had to re-invent themselves to appeal to their clients. Unable to offer direct material support, groups that survived re-directed their energies to economic empowerment through various income generating schemes. Many community-based support groups in Kibera stopped meeting during this period—in part because there was no financial incentive, but also because as people got healthier, they needed to look for work. There were still support groups in Kibera that offered psychological support, but they tended to be tied to income generating activities or directed their activities toward people who had recently started treatment or were bedridden. The ‘crisis’ might have been over, but there were still people in Kibera like Jacob who had been abandoned by their families and in need of HBC, even if it was no longer funded. Nutrition also remained important for the economically marginal residents of Kibera, and existing NGOs and CBOs did their best to get available food to those who were most in need.

In May 2012, after a HAKI support group session, Mathews, a newly recruited support group facilitator, received a telephone call from an MSF Belgium social worker concerning the deteriorating condition of a bedridden HIV patient named Ken. Mathews seemed disturbed as he hung up, saying that the caller had suggested that it would not be long before Ken’s demise. Mathews decided to visit Ken at home, inviting the lead author and a social worker to join.

We found Ken in his humble six-by-six foot room in Gatwekera Village, a ten-minute walk from HAKI’s offices. Matthews opened the closed door when we arrived, calling Ken’s name and welcoming us inside. The room was like most in Kibera, with a cement floor, and walls and a roof made from corrugated iron sheets. The space was divided in two by an old, torn bed sheet. In what served as the living room stood a stool, one chair, a coffee table and a *jua kali* wheelchair,⁴⁰ upon which Ken had piled his medicines. Just beyond the curtain was Ken’s bed. As we entered Ken responded in a feeble voice to Matthews; we could just hear him over a radio tuned to BBC Africa. Ken wanted to sit, but Matthews and the social worker could not get him up. Defeated, he laid on his bed, shaking our hands as Matthews made introductions. When the social worker asked Ken if his brothers had shown up, he shook his head no.

⁴⁰ *Jua kali* refers to the informal economy in Kenya and often to objects made from recycled materials. Ken’s wheelchair had been cobbled together from a white plastic chair and old bicycle wheels.

Prior to 2011, Ken worked as a radio journalist in Southern Sudan. He was flown back to Nairobi when he got sick. Ken's brother, who was also a journalist and sports anchor for one of Kenya's leading media houses, brought Ken to his home in Dohnholm Estate. He took him to Gertrude's Hospital, a private-for-profit health facility that caters to the middle classes. At Gertrude's, Ken tested HIV positive and began antiretroviral treatment. For eight months Ken lived with his brother and family, but did not improve. Eventually his brother kicked Ken out, saying that Ken's illness was interfering with his (married) family's priorities. Although Ken had two unmarried brothers living in Nairobi, they did not have steady jobs and refused to take him in.

His sister—a housewife with two young children and living in a one-room in Kibera—came to his aid. She convinced her husband to find a room for Ken and began washing his clothes, cooking for him and feeding him when he was unable. Ken's brother-in-law helped out when he could, but as casual worker in Nairobi's Industrial Area, he left early morning to queue for jobs and came home late. Ken was taken to one of MSF Belgium's Kibera clinics for treatment. Almost ten months after Ken had been brought to Kibera, none of his Nairobi-based brothers had visited or offered any support despite his sister's repeated requests. Neither had other relatives in the city offered to help.

Apart from asking Ken to sit up and enquiring whether his brothers had visited him, the HAKI staff did not offer physical care or support to Ken during our visit. According to them, it was the family's responsibility care for the sick. After visiting Ken, they moved on to his sister house to ask if she had reached the journalist brother. When she replied that he was avoiding her calls, the HAKI staff advised her to keep trying and to inform them of progress. The HAKI HBC programme had limited resources. They saw Ken's case as one of negligence; because his relatives were financially able to care for him, he did not qualify for their shrinking HBC programme. HAKI also had a team of paralegals, however, and they were considering taking legal action to compel Ken's relatives to support him.

Ken's story shows that in the era of treatment, there is still a need for long-term care of people with HIV. Not everyone thrives on treatment and there are fewer care-based NGOs and CBOs to patch the kin-based safety net. This leads to organizations like HAKI redirecting their energies to compel families to provide care through legal means but also by shifting the moral discourse to blame families for failing to care. In this moral framework, people with HIV are positioned as having the 'right' to receive care from their families, and failure to care is seen as both discriminatory and a shirking of social norms.

Conclusion

Treatment scale-up has brought about a longing for normalization among policy makers and donors, whereby needs for psychological, social, and economic support, to say nothing of home-based nursing care, are downplayed, while support groups based in health facilities become increasingly medicalized to promote drug compliance and reduce risk behaviour (Mattes, 2011; Simbaya & Moyer, 2013; Moyer & Hardon, 2014; Russell & Seeley, 2010). Yet, our research indicates a continued demand community-based care and material support in the age of treatment, particularly in economically marginalized urban locales such as Kibera where family care is sparse and unreliable.

The effectiveness of treatment in diminishing HIV morbidity has meant that funding for HBC activities has also diminished, creating a loss of much needed income for PLHIV who had worked as care providers, as well as a decrease in the care and support that community-based support groups are able to offer to those who are bedridden and not being cared for by their families in Kibera. HBC providers, who were both the backbone and public face of community-based support groups only five years ago, have been forced to disengage from support group outreach activities by economic need. This context has led to resentment and disillusionment within many support groups, but especially those serving lower income areas of the city. Ongoing economic uncertainty affects PLHIV and, ironically, the institutions that have been established to support them, creating much uncertainty about the sustainability of the support group model as a site for reducing self- and community-based stigma, treatment literacy training, psychosocial support and reducing economic insecurity.

Writing about Tanzania, Green has argued that the majority of CBOs are not directly involved in development, but are better understood as 'development agents in waiting' (2012, p. 310). Such a description certainly fits many of the HIV-related CBOs in Kibera, most of which have gone dormant, as HIV community-based funding has declined over the last few years. HAKI, however, has been much more proactive in securing its financial health by investing in various economic schemes to benefit the organization as well as individual members. This was made evident in early 2011 when HAKI's offices burned to the ground in a fire begun in a nearby charcoal maker's hut. Like a phoenix, HAKI rose up from the ashes in a matter of weeks, with new office facilities built with organizational funds and minimal

support from a few benefactors. They even managed to ‘buy’ the land the offices are situated on.⁴¹

CBOs like HAKI, however, are rare. HAKI means ‘rights’ in Kiswahili and the organization, perhaps more than most we have worked with, is actively involved in making rights-based legal claims on behalf of HIV positive people. However, the arguments made in this article intentionally *do not* take up the growing literature on the ‘therapeutic citizenship.’ We do not describe what HAKI is doing as therapeutic or any other form of biological citizenship because the rights-based claims they are making are not about treatment access. Rather they are about economic justice and demands for humane care for people living with HIV. HIV *treatment* is available to the residents of Kibera, most of whom access treatment at one of the two nearby public hospitals or at MSF. Good *care*, however, is not so readily available. As such, HAKI does not take on the Kenyan state, nor do they make claims as citizens of the state. Instead they challenge the families of people living with HIV through home visits, counselling, and occasionally legal cases.

What is happening in the wake of crisis and donor divestment in Kibera then is rather a retrenchment of sites that trained people with HIV to position themselves as citizens (or clients if we are to follow Whyte, et al. [2013]), who might make treatment *and* care demands from donors, the state, or the health facility, into sites where people with HIV gather to ‘reinvent tradition’ and re-moralize family care. Meinert has conceptualized the care responsibilities that shift into the domestic domain in the context of HIV treatment projects as ‘homework’, and argues that the success of this shift relies on a moralizing of the patient-health care provider relationship, resulting in ‘feelings of obligation and responsibility’ (2014, p. 130). She further suggests that questions about patient health and treatment obligations and responsibilities must be re-worked when donor projects inevitably come to an end (2014, p. 131). The findings presented in this article demonstrate that both responsibility for and expectations of care and social support in Kibera have been in constant flux since the emergence of HIV. This is a result of the shifting availability of treatment technologies, including antiretroviral medications, home-based care and support groups, as well as priorities in donor funding and the ever-precarious social landscape of Kibera.

⁴¹ Since Kibera is an informal settlement, one cannot technically own the land, but common law dictates property rights and, since “buying” the land from the previous “owner,” HAKI no longer pays rent.

CHAPTER 6
PUTTING SEX ON THE TABLE: SEX, SEXUALITY, AND MASCULINITY
AMONG HIV-POSITIVE MEN IN NAIROBI, KENYA

Published as: *Emmy Kageha Igonya & Eileen Moyer. (2013). Putting Sex on the Table: sex, sexuality, and Masculinity among HIV-positive men in Nairobi, Kenya. *Culture, Health and Sexuality*, Vol. 15, sup4: S567–580. **Email:** HYPERLINK "mailto:ekageha@yahoo.com" ekageha@yahoo.com

Abstract

Psychosocial support groups provide an important space for people living with HIV to pursue greater wellbeing as they learn how to accept and live with their HIV status. They are critical for the cultivation of responsible and adherent patients. Occasionally, support groups provide spaces where members are encouraged to discuss sexual struggles related to being HIV-positive, including sexual performance issues, sexual relationships, fertility desires, and communicating with sexual partners. This paper examines an HIV-positive men's sex therapy support group at Kenyatta National Hospital in Nairobi, Kenya, where HIV-positive men access information about HIV and treatment, while getting tips on restoring sexual functioning and improving sexual gratification from medical experts, peer counsellors, and fellow group members. In the group setting, members worked to rediscover and reconstruct masculinity under the guidance of a range of experts while focusing on regaining or improving sexual prowess.

Keywords: living with HIV, male sexuality, sexual health, Kenya, support groups

Introduction

This sex therapy group is different from other support groups. We openly and freely put all our sexual issues on the table. When I learned my HIV status I lost hope... you know when peers put their issues on the table and I do the same, their weakness becomes my strength... Before I was very confused how to live and have sex with HIV... since joining this group my life is ok. Kuria (36 year old)

On a Saturday in April 2012, as the main field researcher in a project on HIV support groups, I arrived in Kenyatta National Hospital's HIV Comprehensive Care Centre for the monthly meeting of the HIV-positive men's sex therapy group. The Centre is closed on Saturdays, save for a few scheduled support groups. Unlike the beehive of activity one finds on clinic days from Monday to Friday, Saturdays are unwelcomingly quiet with a watchman controlling admission at the gated entrance. Although it is 15 minutes past the 14:00 starting time, as usual I am among the first to arrive. Only one group member is present. Singing and dancing, an unusually joyful Jeremiah is already mopping the spacious meeting room that serves as the patient waiting room on clinic days.

Leaving Jeremiah to enjoy himself, I wait in the corridor. Five minutes later, two group members and a peer mentor join. By 14:35 Jeremiah is through and welcomes us in. At 14:40, there is a quorum and the group session opens with a prayer from Jeremiah, one of three exceptionally religious group members teasingly referred to as pastors. Following the prayer, reminiscent of Alcoholics Anonymous, the usual sharing of experiences begins with each person, in turn, introducing himself by declaring his HIV status, treatment regime and CD4 count, before presenting any challenges he has encountered since the last meeting. When Jeremiah's turn comes, his reason for celebration becomes clear.

Four years ago Jeremiah had been very sick when he was diagnosed with HIV. Fearing abandonment, he felt it was too difficult to disclose to his wife. Another challenge was figuring out how to introduce condoms in their relationship, which he thought would lead his wife to guess his status. Instead, he 'switched off'⁴² sex, telling his wife it was because he was ill. When his health improved and pressure from his wife increased, he could

⁴² Switching off sex is the colloquial expression commonly used by clients and health care workers to describe the cessation of sexual activity due to physical problems or lack of desire. This expression often allows people to sidestep discussing the sensitive issue of the cause of the problem.

not get an erection. After suffering for some time in silence, he shared his predicament with an HIV counsellor who informed him about a support group that was forming for HIV-positive men with sexual difficulties. Jeremiah was one of the first to join. After a couple of sessions he took his wife for HIV testing where they were counselled together and tested: his wife tested HIV negative. Upset by the discordant results, his wife returned to her rural home, leaving Jeremiah in Nairobi with three children. For two months Jeremiah and his wife communicated through relatives. Although he wanted his wife back, Jeremiah was apprehensive about negotiating sex in a discordant relationship and still worried he might not be able to get an erection. After sharing his predicament with the group, the members advised him to meet face-to-face with his wife to discuss their issues.

Armed with encouragement from his peers, Jeremiah telephoned his wife and convinced her to meet him with a counsellor. On that Saturday in April, Jeremiah triumphantly informed the group that their differences had been resolved and their sex life was alive again.

Jeremiah's narrative illustrates some of the sexuality-related challenges and dilemmas men diagnosed with HIV face, as well as the ways that sexuality is intricately tied to notions of self-worth, psychological well-being, and ability to maintain healthy adult relationships. Despite the plethora of research on HIV, studies on the sexual lives of HIV-positive people is largely absent, addressed only in contexts where prevention of new infections is the objective. Hardly mentioned in scientific literature, policy documents, or clinical practice, sexuality among HIV-positive people is a subject about which very little is known. HIV-positive sex challenges social and medical norms and expectations because sex is the key means of disease transmission. However, for those who are infected, in addition to being a life threatening disease, HIV is disturbing because it has the potential to limit sexuality, which can have serious consequences for procreation, family life, intimacy and pleasure. HIV positive Alex (43 years old) who helped facilitate the sex therapy group summarised the sexual challenges faced by HIV-positive people:

PLHIV need to know they can enjoy sex and still play it safe. In HIV interventions, sex has been limited to safer sex—it is about use of condoms to prevent transmission and re-infections. Introduction of safer sex is the origin of sex dysfunction. Safer sex affects the sexual functioning of men as it causes anxiety. Even in communities, sex with HIV is linked to immorality. Also a condom is a foreign object [...] there have been myths and misconceptions about condoms and therefore you will find some men who just will not

engage in sex at all or will refuse to use condoms. Yet no efforts are taken to explain how PLHIV can enjoy sex even with condoms. Sometime we (HIV-positive people) used to be told we should not engage in so much sex because it will reduce our energy [...] We were told anytime we engaged in sex we reduced our life span. We were scared to engage in sex. In Positive Living (trainings) we were told to abstain from sex because it would negatively affect our health. In fact, even procreation was an issue until Asumpta⁴³ had a baby; that is when PLHIV realised they could also have babies.

In this group, the clinician brings back sex enjoyment. When the facilitator told them they should enjoy sex, most of them were shocked because they know sex is bad; they only have sex once in a while and, in fact, they were not meant to have any sex desire or show any interest.

Background

This research for this paper, which focuses on an HIV-positive men's sex therapy support group, took place in the HIV Comprehensive Care Centre at Kenyatta National Hospital, the nation's largest public referral hospital, located in Nairobi, Kenya. Since 2000, the Kenyan government has led a remarkable crusade to reduce HIV infection. The current prevalence rate of 6.33 per cent is less than half of what it was a decade ago (National AIDS Control Council [NACC] 2011). Innovative interventions to prevent new infections and provide antiretroviral treatment abound in Kenya, and Kenyatta plays an important role in shaping the national response. At Kenyatta, people who test positive for HIV are offered a range of medical and psychosocial services, including the possibility of joining one of fourteen monthly support groups, including ones targeting discordant couples, caregivers, and youth, among others.⁴⁴ The male sex therapy group, when it was formed in 2011, was portrayed to us as exciting and innovative by counselling staff, hospital administrators, and national level HIV policy makers.

⁴³ Asumpta Wagura, the executive director of a national nongovernmental organization for women with AIDS in Kenya, initially forbade pregnancy among group members, but when she had a baby herself, she changed her view, inspiring many HIV-positive people to follow suit.

⁴⁴ The number of groups has shifted over time to accommodate clients' needs and respond to national and international targets. For example, 2013 saw the emergence of two new groups involving men.

Whereas a growing body of biomedical studies demonstrate links between HIV and sexual dysfunction in men (Scanavino & Abdo, 2010; Crum et al., 2005; Moreira et al., 2001; Tindall et al., 1994), very little social science research has been conducted to investigate the consequences of an HIV-positive diagnosis for continued sexuality, and no one to our knowledge has investigated the sexual desires of people on HIV treatment. Scanavino and Abdo (2010) show that negative attitudes toward sex among men infected with HIV can lead to secondary impotence, premature ejaculation, diminishing sexual desires, difficulties becoming aroused and maintaining arousal, depression and suicidal ideation.

The excitement around the men's sex therapy support group at Kenyatta can be partly explained by the shared awareness among those working in Kenya's HIV care services that men's sexuality is rarely addressed by the biosciences in Kenya (or elsewhere), even while it is being stereotyped and targeted for intervention through HIV and gender-based violence programming. The support group, which was the first of its kind in Kenya, served a site of discovery for all participants, including the group facilitators and us as researchers, providing a space to explore sex, sexuality and gender norms as they related to contemporary HIV treatment regimes at Kenyatta. Societal norms connected to HIV, sexuality and masculinity were often reinforced during group sessions. Such norms stressed monogamy, disclosure, condom-use and treatment adherence, which at times contradicted masculinist norms relating to sexual prowess. Exchanges among group participants and between participants and group leaders also provided opportunities for rethinking norms, however. Although HIV treatment norms were rarely challenged, the group offered a space that countered hegemonic notions of HIV as a disease that brought an end to sexual enjoyment. It also brought to light the fact that men with HIV experienced sexuality-related anxieties and distress. The fact that men's sexual vulnerability was being discussed publicly challenged dominant norms about male sexuality within the group, in the clinic, and occasionally in policy circles.

Methodology

This paper draws on a larger two-year ethnographic project on the emergence and transformation of HIV support groups in Nairobi. Here we focus specifically on the monthly meetings of the Kenyatta sex therapy group for HIV-positive men, whose members included twelve men ranging in age from 30 to 52. Three of these men were single (never married),

two were widowers (one re-married), and seven were married with children. Most were economically underprivileged; half were formally employed in low cadre positions, two self-employed, and four were casual labourers. Ten lived in Nairobi's informal settlements, and two owned homes in the city's suburbs. Ten had tested HIV-positive more than three years prior to joining the support group, while two had done so more recently.

Between May 2011 and May 2012, two female researchers (Kenyan and US) attended the monthly men's sex therapy support group to observe and document the ways men were taught about HIV in relation to a variety of sexual health issues and the ways they shared their experiences with one another. Being women researchers did not seem to inhibit men's active participation, perhaps because the counsellor facilitating the meetings was also a woman.

The arguments we present draw on observations of sixteen two-and-half-hour sex therapy group sessions, six in-depth interviews, four key informant interviews, one informal group discussion, and a number of informal discussions with the peer mentor and group members.

Observations focused on documenting sessions, including the content of information provided to members, how information was delivered and received, discussions between experts and group members, discussions among group members, power relations between experts and group members, and group dynamics.

Observations were complimented by conversations held during "walking sessions". After group sessions, it was common for the main researcher to walk for 30 to 45 minutes with some group members from the hospital to Nairobi city centre where they caught busses home. These walking sessions provided a rich environment for informally reflecting, discussing and confirming what had occurred in the group sessions and also gave the researcher opportunity to situate the stories told in group sessions within the wider contexts of men's day-to-day lives.

Key informant interviews were conducted with support group facilitators, including a clinician, a nutritionist, a peer mentor, and a counsellor, to provide insight into the organisational structure of the group and the motives for forming it.

After concluding our observations of the monthly meetings, we conducted in-depth interviews and one informal discussion with group members in the absence of facilitators. These interviews focused on the sexual lives of participants prior to HIV diagnosis, following

diagnosis, and the intervening period until they joined the group; reasons for joining the group; and perceptions of the group.

Ethical considerations

The study was approved by the Kenyatta National Hospital/University of Nairobi's Research Ethical Committee and the hospital's HIV coordinator. Consent was sought collectively from support group members to allow researchers' observation of group sessions and individually for interviews. In the interest of maintaining confidentiality, we did not record the sessions. Instead, with permission from the group members, observations were written in a journal during and immediately following the sessions. All interviews and the informal group discussion were recorded with permission. The names used in this paper are pseudonyms.

Sexuality and masculinity in Africa in times of HIV

Most studies about men, masculinity and HIV in Africa have focused on men as drivers of the epidemic. Often portrayed as inherently problematic members of a monolithic "African" culture that normalises male promiscuity, infidelity, excessive alcohol consumption, and violence, examples of individual African men who break with these stereotypes are rarely seen in the HIV literature. We argue that research conducted within a frame that problematises African masculinity and African men's sexuality is unlikely to offer much insight into the ways that an HIV-positive diagnosis can affect sexuality or masculinity. We agree with social constructivists who argue that gender is relational, plural, fluid and fragile (Connell, 1995; Inhorn, 2012); however, we also argue that the everyday lives of many men are shaped by enduring hegemonic and heteronormative ideas about masculinity that include toughness, stoicism, fertility, aggressiveness and competence in sexual matters (Connell, 1995; Geissler & Prince, 2007; Mfecane, 2012; Tamale, 2011; Tadele, 2011; Wood and Jewkes, 2001).

Men's abilities to meet these norms are significantly challenged by an HIV diagnosis, which may impinge on their sexual and reproductive lives, while also causing emotional and psychological challenges. For many men, an HIV diagnosis brings with it a crisis of masculinity. This crisis arises because of the fraught relationship between sex and HIV.

Among those for whom being a “real man” is defined by sexual potency, a biomedical diagnosis that radically transforms if not terminates sexual activity can have serious consequences for identity making and psychological well-being. The suffering of HIV-positive men is compounded by their desire to conform to another behaviour expected of “real men”: namely, suffering in silence. The sex therapy group allowed a rare space for HIV-positive men to talk openly about sexual problems in a setting where their masculinity would not be called into question. Although the group members were especially enthusiastic in sessions that focused on sexual gratification, they were also very concerned about their ability to satisfy their wives’ sexual needs, their ability to have healthy children, and their ability to meet their economic needs, including the purchase of foods that would enable them to regain and maintain the physical stamina needed for a healthy sex life.

Spronk’s (2009) study of middle-class sexuality in Nairobi notes that modern urban life has brought greater openness about issues of sexuality, particularly in relation to pleasure. She argues that sexuality is a public as well as a private affair and shapes the development of contemporary notions of selfhood among young urban adults (2009, p. 501). We would agree with her arguments, extending them to apply to the lower and working classes of Nairobi as well, but we also argue that recognition and discussion of diverse sexual practices or sexual pleasure remains largely absent from morally framed public (health) discourses, especially those focusing on HIV.

In her seminal critique of Caldwell et al.’s (1989) attribution of high rates of HIV to an African sexuality marked by promiscuity and patriarchy, Ahlberg (1994) set a high bar for social scientists researching the relationship between HIV, sexuality and gender in Africa. One result has been a nascent focus on African sexualities consciously divorced from the pathologizing frameworks found in so much HIV-related research (Arnfred, 2004; Tamale, 2011; Spronk, 2009; Cole & Thomas, 2009). Another has been a growing focus on African masculinities (Morrell, 2001; Ouzgane & Morrell, 2005; Mfecane, 2012; Inhorn, 2009). With the exception of Silberschmidt’s (2004) research on men’s sexuality in Tanzania, however, most research on African masculinities has been located in southern and northern Africa. These bodies of literature make clear that it is impossible to speak of one African sexuality or one African masculinity and further, that the spread of HIV has brought significant social changes across the continent in regards to sexuality and gender norms.

Although much research has been carried out to recuperate healthy sexualities and healthy masculinities in Africa *in spite of HIV*, almost nothing has been written about healthy

sexualities and masculinities as experienced by people *living with HIV*. The few studies that do exist focus almost exclusively on the reproductive desires of HIV-positive couples seeking to conform to heteronormative social ideals (Paiva et al., 2003; Smith, 2007; Moyer, 2012).

HIV support groups in Kenya

Although HIV support groups have existed since the late 1980s in Kenya, an increase in international funding for treatment initiatives in the early 2000s resulted in the proliferation of support groups in health institutions to assist people faced with the challenge of figuring out how to return to normal lives on treatment (Simbaya and Moyer, 2013). Access to antiretroviral treatment, which began to be offered widely in Kenya in 2006, offered a reprieve from death, dramatically altering the life courses of people living with HIV in multiple ways. Concerns about how to reintegrate into social life brought new challenges connected to family life, including marriage and childbearing, both of which normally entail sex (Moyer, 2012). However, as the primary means of HIV infection and re-infection, sex among HIV-positive people has continued to be seen in a negative light, and HIV interventions have appropriated support groups as sites to promulgate ‘safer sex’ and abstinence messages. In most support groups, reduction of sexual partners is encouraged while pregnancy and childbearing are contested. The majority of HIV interventions, including support groups, either overlook or shy away from discussing the sexuality.

Sex therapy for HIV-positive men

The men’s sex therapy support group, which focused primarily on male sexuality issues, differed from the other support groups, which rarely addressed issues of sexuality or the particular psychological vulnerabilities of HIV-infected men. The group also broke with international and national prevention guidelines, which framed sex among infected individuals as inherently risky and in need of containment.

The idea for an exclusively male support group focusing on sexuality was came when a male client attending a mixed adult support group at Kenyatta suggested to Alex, a peer mentor, that men needed a place to discuss issues specific to men that were not appropriate for discussion in a mixed group setting. Although Alex supported the client and wanted to

initiate a group for men, as a peer mentor this was not within his purview. Soon after, however, Maria, a counsellor who worked at the treatment clinic, recognised that several of her male clients who presented with sexual difficulties also sounded depressed, particularly those who could not perform sexually. In her previous work as a physiotherapist, she had noted that men recovering from injuries were often traumatised by uncertainty about their sexual performance. Struck by the comparison, in March 2011 she formed the sex therapy group to provide psychosocial and informational support for HIV-positive men. The group's aim was to challenge myths and misconceptions around HIV, antiretroviral treatment, condom use and sexual performance. She also hoped the group would provide space for men to discuss openly the sexual problems they faced.

In addition to the counsellor and peer mentor who founded the group, hospital staff facilitated monthly sessions: a male clinical officer in his late twenties and, occasionally, two nutritionists (male and female), and a male pharmacist. Sessions adhered to a set structure similar to other support groups: introductions, experience sharing, topical sessions, and finally question and answer time. Topical sessions focused on education and covered basic sexual anatomy, causes and management of sexual dysfunction (premature ejaculation, erectile dysfunction and secondary impotence), the relation between antiretroviral treatment and sexual dysfunction, prevention of mother to child transmission of HIV (PMTCT), infertility, normal and abnormal sexual practices, how to achieve sexual gratification and gratify sexual partners, and the relationship between lifestyle factors and sexual performance, including exercise and nutrition. The men who joined the sex therapy group learned about it from clinic counsellors and peer mentors, from their wives, from other support groups, from morning health talks provided by peer mentors, and a notice posted at the treatment clinic.

Group members experienced a range of physical and psychological issues relating to sexuality that had arisen since being diagnosed with HIV. Although some reported they had become less sexually active as they had aged, all claimed they had not experienced sexual dysfunction prior to being diagnosed with HIV. Three men reported secondary impotence; two single men, one widower, and one in a discordant relationship had switched off sex; two had learned their HIV status when they were very ill and had not regained their ability to perform sexually; and one reported painful urination caused by an enlarged prostate. One suspected he had secondary infertility. The majority who could perform sexually reported experiencing decreased libido or trouble maintaining erections. Another had an HIV negative wife who did not want to have sex. None of the men had previously received information on

safe procreation strategies and they seemed to know very little about PMTCT, despite obvious fertility desires. A few resisted using condoms, opting to abstain from sex all together; others were apprehensive about negotiating condom use.

All group members had participated in other mixed sex support groups before joining. The men acknowledged that mixed HIV support groups helped them to come to terms with their diagnosis, but none had discussed sexual problems in those groups, in part because women were present. Referring to the differences between the sex therapy group and other groups, Kuria (36) reported:

It is for men only...we openly discuss our private sex issues [...] we do not feel shy from sharing, but if we had women in the group I do not think the men will voluntarily open up about their sexual issues [...] it would be very difficult. You know, in mixed adult group we have women who are our younger sisters and mothers [...] it becomes difficult to share.

“It is better to be born impotent...”

Sex therapy group sessions, provided a space for group members to discuss sexual issues and (de)construct masculinity norms as they related to sexuality and family life. For example, prior to joining the sex therapy group, Kamau (50 years old) was frustrated by his inability to get assistance with his sexual problems. The story he shared the first time he joined the group demonstrates how this affected his psychological well being and intimate life:

When I was discharged from hospital I had a catheter and could not perform sexually [...] I found myself useless [...] you feel that is the end of the world [...] you do not see the need to live. When my health improved I would perform minimally, but this gradually reduced and in the end I was impotent. I was in another world. I attempted suicide. For the last two and a half years I have told my impotence experience to different doctors who put me on drugs that did not work [...] would go to the clinic where I got my ARVs and explain my sexual problems to one doctor after another [...] the doctors would just note in my file and prescribe some medicine but nothing happened [...].

I even hated my wife, whom I blamed for my sex failure, but at the same time I used to think it was unfair to her because I couldn't fulfil her conjugal rights [...] this frustrated me as a man; many times I asked her to leave. I even went ahead to try with another woman but I failed to get an erection. Sometimes I could feel the desire for sex but I just cannot get erect. I

had been thinking it could be the effect of the catheter or ARVs, or the overdose I took. I kept asking myself where my sexual prowess disappeared too. Being a man, I have never discussed my problem with anyone other than my wife. The last three years when I was impotent, I isolated myself from my friends [...] I did not want to meet with them...there was much going on in my mind.

Usually, after sharing of experiences members are called upon to respond. Discussions are normally vibrant, but in this instance no one responded. Eventually one said, "You are welcome... you are at the right place... some of us have gone through your experience". The facilitator, who was a medical doctor that day, focused his talk on HIV and causes of sexual dysfunction. He later gave Kamau an appointment.

At the next session, an enthusiastic Kamau shared his success:

Since joining this support group, sharing experiences and working with Dr. Furaha who referred me to another doctor for further management, life has been very good [...] my wife is very happy...we are very happy. I feel alive again. I was put on medicines (sildenafil citrate [Viagra] and mega vitamin tablets) to take two hours before playing sex, but even without taking the medicines for two days, I still perform very well...I have two children only and soon they will leave me [...] Sex makes life... even if I do not have much money, with my sex life back life is very much ok.

When Kamau finished one member clapped for him and another said: "It is better to be born impotent...you deal with it, but it is very painful to become impotent after being sexually active." This was followed by the rest of the group echoing, "Yes, very painful!"

Although most of group members' talk about sexuality was entirely phallogocentric, as Ratele (2011) has suggested, the significance of the penis in any man's life is never just about the organ as a physical object. Rather, it is more about the powerful meanings that the organ accretes; for many men (and their female partners), masculinity is closely tied to sexual performance. Overall, group members were most concerned with what the penis *should* do: perform sufficiently to allow them to achieve their own sexual gratification, to fulfil conjugal duties, and to procreate. Kamau shared in a focus group session:

Every time I am unable to perform, my wife tells me to get rid of my thing (penis) because it is useless. I feel so useless, hopeless and worried. I am anxious whenever I am with my wife.

Most men wanted to perform sexually to maintain healthy relationships with spouses and partners; Kamau seemed too long for days of former glory. "I was Akuku Danger," he boasted, comparing himself to a well-known Kenyan who married 100 women and had so

many children he was forced to construct a school exclusively for their use. A few others, while not as prolific as Kamau, also reported having had multiple sexual partners prior to encountering their current problems. The clinician-facilitator repeatedly informed them that factors other than HIV could contribute to their sexual problems, however, group members continued to see HIV as the cause of their inability to perform sexually.

Njoroge (46 years old), another group member, discovered his HIV status before showing symptoms when he was asked to take a test as part of a job interview in 2004. Despite being otherwise healthy, he switched off sex, began to hate women, went on drinking sprees, and twice tried suicide. As he told his story, the others interjected a chorus of “Yes!” at key moments, collectively endorsing the link between an HIV diagnosis and diminished libido:

(T)he truth is, for every man when they get to hear the announcement of HIV-positive, it automatically negatively affects men’s sex urge...the sex organ and urge go dead...(YES!) ... You lose sexual desire. I was at that point [...] I was in denial [...] I attempted suicide twice [...] I turned to drinking alcohol [...] at some point for three weeks I was only living on alcohol...I did not eat anything because I wanted to die [...] I hated women [...] joining groups saved me... (YES!).

Kamau’s and Njoroge’s cases are typical in that they demonstrate how men’s sexual struggles can lead to major worries, putting their sense of self and the very meaning of life in question. For most men in the group, being able to perform sexually was equated with being ‘alive’, a ‘real man’ and an important source of their happiness.

The problem with condoms

Within the context of sexual and reproductive health programmes and HIV interventions, condoms are promoted for family planning and safer sex. Many, however, claim that condoms interfere with sexual performance and limit sexual pleasure. Using condoms can be particularly challenging in long-term relationships, because they are associated with infidelity, but also because people believe that having sex without condoms is a reward of long-term relationships. Whereas Heyer et al. (2010) show that condoms were often the only topic related to sexual matters discussed in support groups, usually the focus was limited to the difficulties women had in convincing men to use them. The underlying assumption was

that men did not want to use condoms. This resistance by men has long been portrayed in literature on HIV prevention as a result of some sort of innate need for men to dominate. Among the men in the sex therapy group, however, condom use emerged as a primary cause of sexual anxiety; some had abandoned condoms altogether, some did not use them consistently, while others did not feel confident discussing safe sex and condom use with their wives or other sexual partners.

John (30 years old) the youngest and most recent member of the group had not had sex since falling ill and learning his status. After attending a couple of sessions he asked, "So is it ok to have sex with a condom?" John informed the group that now that he was recovering from his long illness, his girlfriend was pressuring him to have sex. He had been avoiding her because he did not know if it was possible to engage in sex without infecting her. Three other men also reported challenges with condom use: one stopped engaging in sexual activity because he could not tolerate condoms, another reported that he "felt itchy" after using condoms, and a third claimed he could not sustain an erection while wearing a condom.

My wife lived in the rural area, and when she came to Nairobi, I did not disclose to her...I just had sex with her. Later I suggested we take a HIV test together. I tested HIV-positive; she tested HIV negative. We were enrolled in the discordant couple clinic here in Kenyatta for two years. I was told to use condoms whenever I had sex with her. I hated this condom [...] and later I decided if it is using condoms then I will do without sex.

Across the board, men in the group seemed to have relatively little knowledge about how to use condoms; even if they understood the mechanics, they were unsure how to negotiate condom use with their partners or how to enjoy sex while wearing a condom. During group sessions, condom use was promoted as a tool for safer sex, for family planning and, most attractively, maintaining an erection. Myths and misconceptions about condoms were explained, and an extensive demonstration was given. Following the session on condom use, several members reported they had satisfactorily used condoms; a few were quite positive, claiming condoms had helped them to delay ejaculation and did not hinder pleasure.

Sexual gratification and fertility

While group facilitators tried to keep discussions focused on HIV, antiretroviral treatment and the specifics of sexual dysfunction, group members usually succeeded in steering the discussions toward sexual gratification and fertility. Sessions that focused on sexual gratification and fertility elicited greater and more enthusiastic participation by members and always lasted longer than the set time. Infertility focused on quantity and quality of semen, and enlisted many concerns and questions. Gratification talk focused on achieving orgasm, setting the scene for sexual activity through communication, music, dressing, lighting and environment, foreplay techniques, how to delay ejaculation, sex positions, quantity verses quality of sex, frequency and enhancing partner participation in sex.

The limits of group therapy

Studies on support groups focus mainly on the positive, however, support groups also have limitations that deter participation. Despite good intentions, some information provided by experts de-motivated group members and some information was based on personal views rather than scientific evidence. For example, the counsellor-facilitator regularly informed the men that some sexual dysfunctions could be blamed on masturbation. Although group sessions included question and answer time, group members did not usually question the experts, saving their critiques instead for our post-group walking sessions.

In once memorable group session, for example, the seasoned nutritionist who was facilitating asked the men about their sexual performance expectations. He asked them how many sex rounds they had in a week. With the exception of Jeremiah, who had recently reunited with his wife and reported having three rounds a day, the rest were averaging two per week. The nutritionist then asked them all their ages, after which it seemed he did some quick calculations before informing them that men their age should have a “daily dose” of 2-3 rounds, and that those who did not have sex for six days should be able to go six rounds on day seven.

With eyes opened wide in shock, one amazed member exclaimed, “six rounds?!” Another added, “that was long ago when we were young; we could even have eight rounds!” All members of the group, myself included, sat in quiet awe as the facilitator informed us about the foods that would enable this to become a reality. Among them were pumpkin seeds,

which after the session became a much sought after item. At the time, a 250-gram packet was selling for 250 Kenyan Shillings (about 3 US dollars), a high sum for the group members. The practice of prescribing foods for enhancement of sexual performance that were impossible or expensive to obtain in Nairobi was fairly common. On another occasion men were advised to eat strawberries and oysters regularly, neither of which were easy to come by in Nairobi.⁴⁵ At the same time, when group members brought up the possibility of using traditional remedies to treat their problems, some of which could be obtained cheaply and easily in local markets, they were summarily discouraged by claims that herbal medicines would interfere with their antiretroviral treatment.

Although the facilitators claimed that they wanted group members to participate actively and openly, members were occasionally quite obviously intimidated and silenced by facilitator power plays. Following an informal group discussion with support group members, the participants continued on to a sex therapy group session. During the procedural introduction, John, who had just shared in our informal discussion that he was not using condoms and had stopped taking Septrin, introduced himself in group therapy, mentioning that he was in a discordant relationship and had stopped taking Septrin. A guest facilitator, who was a nurse-counsellor at the clinic, gave him a harsh look and asked, “And you are using condoms?” John, avoiding eye contact with the counsellor, smiled and quietly responded, “yes,” before retreating into silence for the rest of the session. In this instance, we can see the nurse’s authoritative moralising led John to shut down.

Information shared by some support group members could also cause stress among other group members. During introductions, members routinely reported their CD4 count, a biomarker used to measure both treatment success and health. Some of those with declining CD4 counts would express sadness and worry, while others hoped for an increase. On a day when a member with a 1400 CD4 count was absent, one group member said, “Hey, John’s CD4 is very high and that demoralises me,” prompting others to admit that they also felt stressed when John reported his CD4 count.⁴⁶

⁴⁵ The absurdity of such advice becomes particularly poignant when analysed from a perspective that takes seriously the challenges most people on HIV treatment in Kenya have in meeting daily nutritional requirements (cf. Prince, 2012).

⁴⁶ Clients are put on antiretroviral treatment when their CD4 count drops below 350. 1400 is exceptionally high for someone on treatment.

Despite the exceptionally liberating aspects of the men's sex therapy group, as in all support groups, there were also risks. The space could be used by facilitators and other members to impose both biomedical and social norms to condemn individual behaviour; biomedical personnel, under the guise of expertise, could veil moral stances with scientific claims; and interactions between group members could have a demoralising effect, particularly on members who were struggling. Given the experimental nature of the group and the fact that facilitators had received no specific training in addressing male sexual issues, it sometimes seemed as if health care personnel were piecing together what they considered to be a rational and reasonable response to the challenges the men reported. As medical experts, their opinions and advice were taken very seriously and their expertise rarely questioned, even in moments when they were clearly engaged in moralising.

Conclusion

This paper offers a glimpse into the sexual vulnerabilities experienced by HIV-positive men in Kenya. Male sexuality is a topic that is routinely overlooked in gender-based health and development programmes in Africa, including those that target HIV-positive people. Given the paucity of existing research on this topic, we have tried to address a gap in the growing literatures on masculinities and sexualities in Africa by focusing on the sexual lives of HIV-positive people. Our findings demonstrate that, although men's sexual anxieties continue to be shaped by hegemonic masculine norms tied to sexual performance and the phallus, men's sexual concerns are also shaped by fears about infecting their partners, lack of knowledge about and ability to negotiate condom use and safe sex, wanting to fulfil their partners' sexual desires, and wanting to father HIV-negative children.

We have illustrated the wide range of the sexual struggles experienced by men living with HIV and have shown the degree to which they can benefit from group therapy sessions, where interaction with people they consider their peers results in psychological improvement for most, and some degree of physical improvement for many. We found that actively participating in the sex therapy group benefited members. All participants reported progress in fulfilling sexual desires after joining the group, and claimed they benefited from the information they received from the experts and experience sharing. Some announced their intention to have children after receiving information on PMTCT, which, they had previously

lacked. However, we have also shown that some information can have unintended negative effects on members.

Health-facility based HIV support groups in general, and the men's sex therapy group specifically, simultaneously serve as sites of potential liberation and moralisation. Although this group was established as an experiment meant to bring relief to men suffering from sexual difficulties and to create a space where the sexuality of HIV-positive men could be openly discussed, group facilitators risked alienating individuals when they espoused norms related to HIV discourse, condom use, adherence, and pregnancy. Shielding themselves with claims of biomedical neutrality, these experts sometimes instituted silences instead of the openness toward which they claimed to be working.

CHAPTER 7
MY BROTHER'S KEEPER:
CARE AND SUPPORT AMONG MALE SEX WORKERS

Introduction

Whatever men who have sex with men [MSM] who sell sex do is pegged on money. Even for them to meet me for an interview, I had to pay them. I noticed that they do not consider HIV as a threatening issue. All they talk about is [how] to get money and clients. They feel HIV programmes without money are a waste of their time. They do not even use protection such as condoms. This, in a way, defeats the purpose of having a support group. To them a support group means coming together to get money. On some occasions when I told them there was no money, they would not turn up to meet me. Furthermore, in their support group, they do not discuss anything about HIV. They are more concerned about human rights issues and clients. (Director of a local HIV NGO)

Beginning in 2009, much of the HIV funding and many HIV interventions in Kenya shifted towards key populations, including MSM and sex workers. The above quote illustrates one of the key challenges that NGOs have had in reaching poorer MSM, especially those who engage in sex work as a primary means of income. Such men are, understandably, often more concerned with the day-to-day difficulties they encountered with police and clients. The MSM sex workers with whom I worked were mainly preoccupied with matters to do with their survival: money, clients, and their own human rights. They often complained that HIV interventions did not recognize issues of survival, which they considered to be most pertinent, drawing attention to 'the ways objectives of global health interventions shape particular social spaces' (Rhine 2009, p. 370). My observations of HIV interventions targeting male sex workers supported their contention: for the most part, they failed to focus on the struggles that MSM sex workers go through in their daily lives.

MSM sex workers lead lives marked by uncertainty, violence, and homophobia, evoking feelings of fear, anger, anxiety, powerlessness, hopelessness, a sense of low self-esteem, and tensions related to their sense of self and belonging (see Niang et al., 2003; Khan, 1994, 2001). As is the case for many other socially and economically marginalized people around the world, HIV was rarely considered to be the biggest problem they faced (Farmer, 2006); matters of daily survival, identity issues, frosty kin relationships, and human

rights concerns, as well as a longing for love and pleasure, were much more salient to MSM sex workers. The quote above expresses typical sentiments of those working for NGOs that ran HIV-related interventions that targeted MSM sex workers: they generally downplayed issues pertinent to MSM sex workers, focussing almost exclusively on HIV prevention in the support groups they sponsored. These HIV interventions aimed at instilling responsibility in MSM sex workers, but in doing so ignored their economic, political, and emotional concerns. Workshops intended to empower and make them take responsibility often contributed to feelings of disillusionment or alienation. Still, interventions targeting male sex workers provided a springboard for MSM sex workers to come together and reconcile their three identities – being HIV positive, being homosexual, and being sex workers – to find new ways of being, surviving, and very occasionally thriving.

In this chapter, I focus on a particular group of MSM sex workers who made up an informal and organically formed support group known as ‘Freedom Corner’. Below I present an already published case study of Freedom Corner (boxed text). This will be followed by descriptive accounts of the informal conversations I encountered during my research at Freedom Corner, highlighting the ways Freedom Corner provided a forum for young MSM sex workers to interact and work on their identities. I focus particularly on discussions of sex, sex work, and pleasure in an attempt to highlight the ways that health related risks – HIV as well as tuberculosis and sexually transmitted infections – are entwined with efforts to make a living and to make a life worth living. Lastly, I explore the psychic traumas that the men from Freedom Corner associated with being HIV positive, being homosexual, and being sex workers. First, however, I want to sketch the contemporary legal, political, and social context of homosexuality and homophobia in Nairobi today.

Homosexuality, sex work, discrimination, and the law

Like in many sub-Saharan Africa countries (Lorway, 2006, Niang et al., 2003), in Kenya, the (re)criminalization of homosexuality under section 154 of the penal code has been accompanied by moral discourses by political and religious leaders, ostensibly contributing to a rise in violent, homophobic acts directed toward MSM. Paradoxically, human rights discourses advocating for homosexual rights and public health discourses linking HIV and homosexual sex seem to have increased public expression of homophobia, as well as violence

toward men presumed to be homosexual in Kenya. At the time of this study public debates about homosexuality and sex work, shaped by public health, human rights, and moral discourses, become increasingly prominent.

In 'Dispelling "Heterosexual African AIDS" in Namibia: Same-Sex Sexuality in the Township of Katutura', Lorway (2003) highlights homophobic rhetoric among political class and Christian associations drawing attention to the connection between homophobic rhetoric and access to health services. In Kenya, religious and political leaders have condemned homosexuality and sex work as 'immoral', 'corruption', and 'pollution' of the nation, could be connected to access to health services, and also to citizenship. For example, homosexuality was much highlighted during Kenya's 2010 constitution referendum and the hiring of Chief Justice Dr Willy Mutunga and his deputy, Dr Nancy Baraza. And in 2011, Kenya's minister of special programmes, Esther Murugi, was denounced by religious and political leaders when she called for tolerance towards MSM during the launch of an HIV key population intervention. On 2 October, 2010, the *Daily Nation* reported remarks by two Muslim sheikhs. The first said, 'God in his holy books curses homosexuality and directed us to fight it', and the second, 'The Minister and NACC officials should create their own country which allows homosexuality, lesbianism and prostitution acts'. During the 2013 Kenyan presidential campaign, President Uhuru Kenyatta and his deputy William Ruto, in response to the call for gay rights by US President Barack Obama, stressed that Kenya is a God-fearing country that upholds Christian values and does not conform to 'gayism' (*sic*) (The Kenya Television Network, 30 June 2013).

Whether media reports contributed to or intensified enacted homophobia was not the object of my study. However, what is clear is that members of the Freedom Corner experienced homophobia at the time of my study. Forty-one-year-old Halima,⁴⁷ a MSM sex worker who had been working in Mombasa, relocated to Nairobi after he narrowly escaped being lynched by enraged community members, and Mary (35 years old) regularly shuttled between Nairobi and Mombasa for safety. Those who remained in Nairobi were always relocating within the city whenever they sensed danger. For example, 25-year-old Constance, who lived in Nairobi's Eastlands neighbourhood, relocated to another part of the city when his neighbour began to suspect that Constance was gay.

⁴⁷ Pseudonym. I explain below why I opted for female names for MSM sex workers.

Two weeks prior to the end of my fieldwork, five of the men from Freedom Corner informed me that they had relocated from the Dandora neighbourhood after the outlawed Mungiki gang in Eastlands banished them from their houses. The Mungiki gang, who were themselves outlaws, felt comfortable calling the police to arrest the men from Freedom Corner, and warned them never to return.

In addition to harassment from neighbours, the men at Freedom Corner were also harassed by church members and religious leaders. Miriam (29 years old) sobbed when telling the group how a church minister excommunicated him from the church's choir: 'During one Saturday's choir practice, the church minister came around and ordered, "the *Shoga* in the choir should leave". Everyone was quiet. After a minute he repeated, "the *Shoga* should leave"'. Although Miriam had not disclosed to anyone in church about his sexual orientation, he walked out of the choir and relocated from his residence to another part of the city.

Similarly, men whose appearances did not conform to gender norms or who had come out publicly as activists regularly came under attack in public spaces. One early evening in December 2012, Latifa, Georgina, and I were joined by Joyce and Carol at Freedom Corner. They were seeking refuge. They told us how they had been chased by irate members of the public when they were spotted in a restaurant in the Ngara area of Nairobi, a kilometre away from Freedom Corner. They had appeared in *The Star Newspaper* on 1 December 2012, recounting their life experiences and involvement in mobilizing MSM sex workers to access health services. John and Marion, both of whom were activists who advocated for the rights of MSM sex workers and who had appeared on Kenya Television Network's three-part documentary on male sex work, were forced into hiding after receiving threats via phone from anonymous callers. During the 'End Violence against Sex Workers' street processions, in which I also took part, some visibly irritated public onlookers shouted at us: 'We do not want *shogas* – such behaviour is unacceptable in our society'.

Some responded to such pressures by attempting to pass as heterosexual in public, altering their dress and appearance. When I met Joyna (25 years old) he had dressed in tight-fitting clothes and carried a ladies' handbag. I was surprised when he showed up at Freedom Corner one day minus his handbag, wearing baggy sports trousers, a baggy hooded sweatshirt that covered his head, and sneakers. When I asked him about his change in dress, he answered, "I want to be at peace with the society. I do not want to show I am gay. Those who are interested in me can see it from my baggy clothes'.

Prohibitive homosexuality and sex work laws in Kenya put the lives of the men who worked at Freedom Corner in danger. When they were attacked or threatened, they did not dare go to the police. In the face of threats from family, neighbours, religious and political leaders, police, and the state, homosexuals, sex workers, and their supporters have begun to make public demands for health and human rights through protests and speaking engagements in recent years. Since 2005, sex workers' rights organizations have emerged. These include Kenya Sex Work Association (KESWA) and Health Options for Young Men and AIDS (HOYMAS), which advocate for female and male sex workers' human rights. Under the glare of the media, activists have demanded the decriminalization of sex work, respect for sex worker's rights, safe work stations, and an end to police harassment. All Freedom Corner group members joined HOYMAS. In addition to the care, support, and other work and social activities that unfolded at Freedom Corner, HOYMAS and KESWA activities were planned there. Freedom Corner provided a safe place for planning activism and gave members the opportunity to mobilize other MSM sex workers.

Clearly, stigma and discrimination toward homosexuality and sex work was prominent in Nairobi at the time of my research. This could be witnessed in the media and in legal contexts. Yet, for many men who identified as homosexual or regularly engaged in homosexual sex, the greatest challenge was the stigma and discrimination by their families that they experienced, something that greatly contributed to the psychic wounds that so many of them carried.

Hussein, who was 39 at the time, was one of the first gay men I met during my fieldwork. We became acquaintances and met occasionally over a cup of tea to discuss my research. Although he was not a sex worker, he told me how he struggled to accept himself as a gay person, a sexual identity that he had tried to deny or run away from by all means. He claimed it had even robbed him of the love of his family. He worked as a consultant for MSM-led NGOs and CBOs, and hustled with petty businesses when not engaged by the NGO and CBOs. Hussein had to contend with what I call 'economic affection' – a relationship that was based on his ability to provide monetary assistance to his kin. His family feigned affection for him in exchange for monetary support. Recounting how he tried to resist his homosexual longings, he told me:

When I realized I was attracted to men, I hated myself. I even tried to commit suicide simply because I did not have someone to talk to. I knew it was a bad thing in a largely heterosexual society. I feared homophobia. I was experiencing something I did not want to be part of. I did

the best I could to understand what was wrong with me. I prayed, asking God to get the feeling out of me, to change this feeling. ... I did not want the feeling. I did not want to be something that I did not want. When my parents and siblings came to know, they rejected me. I even married a woman and had a child, because I wanted to be normal, but I was still attracted to men. My wife and I parted ways, and she left me with the child. One of my sisters really hated me. But after her husband died I'm the one who pays for her children's (school) fees. I also financially support members of my family. However, even as I help my family members, none of them ever calls just to find out how I'm doing or say hi. When they call they just give me a list of their economic demands. They will call again when they are in need and never say hi or thank you. I work hard to keep this relationship by making sure I have money so that when they call I send it to them.

Hussein's narrative reveals the harsh social environment that MSM encounter. Many of the men at Freedom Corner had cut ties with their kin. A few like Hussein, however, maintained the relationship. Others who had been previously rejected also reported being accepted by kin when their economic fortunes changed. For many, their strained relationships with their kin, both in the present and in the past, contributed to stress and emotional trauma. They felt hated and rejected by family as well as by society. Freedom Corner offered a place where brotherly love could occasionally be found, where friends did their best to stand in for families that failed to care for their homosexual sons.

**Freedom Corner: redefining HIV and AIDS care and support
among men who have sex with men in Nairobi, Kenya**

Emmy Kageha Igonya & Eileen Moyer (2016)

Published in *Routledge Handbook of Medical Anthropology*, L. Manderson, E. Cartright and A. Hardon (Eds.), 75-80. New York: Routledge

Given the current political and legal climate around homosexuality in East Africa, we jumped at the opportunity to include a case study of male sex workers in our ethnographic project on the new forms of social support that have emerged in Nairobi over the last several decades in the wake of the HIV epidemic. In most instances, the "gay community" of Nairobi is a few articulate and educated homosexual men. Because homosexuality remains illegal, if somewhat tolerated in Nairobi, these gatekeepers,

quite rightly, tested us for several months before introducing us to the underworld of male sex work in the city. Most likely, we could have used our clout as researchers to engage with these same men through one of the public health interventions currently targeting them. Hoping to distance ourselves from such interventions, however, we decided to go through community gatekeepers, building rapport and trust slowly over several months. We did attend and observe public health events and activities focusing on HIV treatment and prevention among “men who have sex with men,” or MSM, but only in the company of our research participants. Most of our research took place in informal settings, relying heavily on observation, conversations and “deep hanging out” in a bar in downtown Nairobi where male sex workers gather in the early evening before hitting the streets.

Here, we offer a glimpse into a space of unexpected social support, where young men living in extremely precarious circumstances become their “brothers’ keepers.” In this space, known as Freedom Corner, men collectively engage in impromptu performances of “gayness,” assigning one another female nicknames and sashaying about in tight clothes as they drink cheap beer, flat and warm. In between the sometimes forced frivolity, they check up on one another and offer advice on ways to be safe from gay bashing and other forms of gendered violence, from HIV, and from the police. As a social group, these men also support one another when attending NGO sponsored activities, sometimes taking over those spaces to voice their frustrations with one another’s behaviour and to seek allies among NGO staff to pressure their peers. At other times, they demonstrably disengage, showing up to collect “transport allowances” and offering little to the forced discussions.

We refer to these men as “men” while using the female names they prefer to use when they are together. This is purposefully done to bring a degree of gendered tension to the description, replicating the gendered tension that characterizes their day-to-day existence. When performing their particular version of “gayness,” they refer to themselves as *shogas*, a Kiswahili word referring to effeminate homosexual men; when performing for the public health world, usually as people living with are at high risk for HIV, they refer to themselves as MSM; when alone together, they define themselves as male sex workers, appropriating the term *kuchu*. They use this term because it is

unfamiliar to most Kiswahili speakers, but widely known among homosexuals; it suggests their sense of shared oppression. In our text, we use all these terms consciously, depending on the context.

Freedom Corner

When we first began working with them, they did not even define themselves as a “group.” Our identifying them as a group and giving them a name served as an act of interpellation, increasing a sense of group identity, the identification of leaders, and lending language to their growing political consciousness. We were immediately pulled into their political project, and asked to participate actively – making referrals to health care, offering advice, pressuring non-compliant peers, and making financial contributions when money was collected to aid a fellow in need.

The name Freedom Corner derives from the famous historical spot of the same name located in Nairobi’s Uhuru Park (Mathaai, 2007). The late Nobel Laureate, Professor Wangari Mathaai, named Freedom Corner when she and other activists held a hunger strike there to pressure the government to release political prisoners. The *kuchus* identified with Mathaai’s political activism; for them Freedom Corner symbolized their longing for freedom and safety as citizens of Kenya and their struggle against the triple discrimination they faced as HIV positive, homosexual, sex workers. The run-down bar that housed Freedom Corner was located in Nairobi’s downtown River Road area, sandwiched between two shops. The owners of the bar tolerated the *kuchus*, who were accorded the back corner of the establishment. Freedom Corner was spatially marked out by four long benches arranged in square, at the centre of which was a low table, usually filled with plastic beer mugs topped with drinking straws. The space could comfortably accommodate twenty people and often overflowed as the evening picked up. Most notable about the space was the overpowering smell emanating from the toilets, less than two meters away. The first door-less toilet was used by men who stood in the corridor when urinating. When visitors expressed concern with the deplorable and unhygienic state of Freedom Corner, they were quickly told that compared to most places sex workers congregate, Freedom Corner was “high class,” and that the cheap beer on offer was comparatively expensive. The *kuchus* felt at home at Freedom Corner;

there they could relax, tell stories and jokes, and not worry about harassment from police or homophobes.

Participation in the group was purely voluntary. There were 24 core group members from diverse ethnic backgrounds; all except one came from relatively poor families. Nineteen were primary school dropouts, three secondary school dropouts and two had attained tertiary education. Poorly paying sex work was their main source of income, although eight occasionally also worked as peer educators in various programs targeting MSM sex workers, for which they received a monthly allowance. HIV training allowances supplemented their income. Occasionally, a few engaged in petty business.

Everything at Freedom Corner was impromptu: no group facilitator and no agenda. With a fluid quorum, those who hung around Freedom Corner updated others on what had transpired in their absence. Text messages were shared, in part because the messages concerned everyone, and because the majority did not own phones. The *kuchus* of Freedom Corner were welcoming to visitors, including male transgenders, *kuchus* from Mombasa, and less often, current and ex-boyfriends, lesbians and female sex workers. *Kuchus* socialized with one another and visitors while drinking, smoking cigarettes and chewing khat; they laughed, gossiped, quarrelled, cried and engaged in various discussions collectively or in smaller groups; they networked for group sex, shared security alerts and organized participation for HIV training workshops and street advocacy; and mobilized support for those who were ill. Discussions covered ailing colleagues, abuse by clients and police, security, sexual practices and experiences with homophobia, health issues and nutrition.

My brother's keeper

The majority of *kuchus* had cut ties with family and kin, often referring to the Freedom Corner group as their family. Most were homeless. On a "good" day, when they had clients, they might sleep in cheap lodgings (about US\$5 per night). On bad days, they would either sleep on the streets or seek temporary shelter from colleagues who had managed to rent a place for the night or week. Some exchanged sex for a place to sleep. They drank and ate cheaply, sponsoring one another when able.

Only two members received occasional support from their mothers. A few who had requested support from family had been denied or told they would only be helped if they first denounced their sexual identity. *Kuchus* consciously invested in the group, providing social support to colleagues and peers in anticipation of reciprocity. They worked together to care and support sick members of their community. Although many suffered from minor health ailments as a result of poor nutrition and sleeping on the streets, periodically, some required extensive care when they suffered from HIV-related opportunistic infections. In such instances, the sick were taken in by colleagues who would do their best to nurse them back to health—bathing, feeding, ensuring access to medication and treatment, taking them to the clinic and updating the others who were expected to provide economic support. This monetary support was meant for the sick person, but also those who missed work to care for the sick. Group members also offered emotional support and encouragement to sick members and those providing care. Those who were very sick were hospitalized, in which case group members would visit, bringing food gifts and paying hospital bills, either out of pocket or by mobilizing support from HIV intervention projects (and willing anthropologists).

Because of the heavy burden of HIV-related care resulting from poor treatment adherence, it was common for group members to pressure those on antiretroviral treatment to take their medication, to eat well and to refrain from excessive alcohol consumption and smoking. Members also often shared medications. Because most were homeless and rarely slept in the same place from night to night, they were often caught without their daily dose. Not everyone in the group had HIV; several were probably HIV positive but were not open about their status until they were too sick to hide it. For as much as there was support in the group, there was also stigma. Being known to be HIV positive affected one's ability to find work, as other, presumably HIV-negative, sex workers were not above stealing clients from those known to be positive, disclosing their status to gain the upper hand.

Disappointing development

Although the Freedom Corner *kuchus* were heavily targeted by NGOs and had come to depend on them for medicines and occasional income earning opportunities through trainings and workshops, the most important source of support for most of them were

the friends they had made among their colleagues at Freedom Corner. In fact, most felt discouraged by the NGOs that tried to help them. As the example below demonstrates, the training seminars offered by NGOs rarely addressed the underlying economic, political and emotional concerns of *kuchus*. Workshops intended to empower, more often contributed to feelings of disillusionment.

In recent years, Nairobi has been the site of various public health interventions aimed at reducing HIV risk among the “key populations,” including sex workers and MSM. The *kuchus* of Freedom Corner have high “biovalue” in this global health context, in which aid organizations and researchers often have trouble recruiting participants for planned intervention and research activities. Members of high risk communities are usually by definition hard to reach, resulting in a paradoxical scarcity that means aid organizations often share clients, and the same MSM repeatedly serve as key informants for diverse research projects. The *kuchus* of Freedom Corner were aware of their value in this context and did not hesitate to capitalize on it when possible.

As “targets” of global health interventions, they are invited to many trainings and workshops, where they are given advice on subjects intended to educate and empower them, with the assumption that such interventions will motivate them to protect themselves, their clients, and their lovers from HIV infection by using condoms and taking ARVs, both made freely available to them. Their lives, however, are characterized by violence, uncertainty, fear, powerlessness and anxiety. *Kuchus* are more concerned with day-to-day survival, homophobia and identity issues than they are with negotiating condom use with paying clients. Hence the disconnect between such trainings and their MSM targets, as one of us – Emmy – experienced.

On the morning of 23 August, 2011, 25 MSM aged between 25 and 45 gather in a small room on the 8th floor of one of downtown Nairobi’s three-star hotels for a harm-reduction training on HIV, Alcohol and Substance Abuse, facilitated by the USAID-funded AIDS Population and Health Integrated Assistance (APHIA*plus*) project.

A middle-aged Kenyan woman, I sit in the back row and observe the proceedings. To my left is a young man I know as Maggie; dressed in an oversized jacket he sleeps, slumped

over his desk throughout the three-hour session. All is calm as the facilitator reviews the previous session. When he asks the participants to evaluate their “self-concept,” however, Carol, another young man, begins weeping uncontrollably and the room falls silent. A participant places a hand on Carol to console him, while others look to the facilitator to intervene. After a few uncomfortable moments, the facilitator asks Carol what the problem is. Looking at the ground, he responds: “My life is wasted...I did not know I would end up as a sex worker and also infected with HIV (he sobbed)...I was a bright boy but dropped out of school for lack of school fees...I feel so useless and wasted.”

Carol’s outburst transforms the previously boring training into a support group session. His friends perk up and gather around, taking turns to offer support, but also to direct remarks to others in the group. Jemima begins with a statement to build unity by offering a critique of donor-sponsored events like the one they are attending. He follows this with the message that they must take care of one another, but also declaring that each person is responsible for his own health.

We are our brothers’ keeper. We are shogas... kuchus and sex workers. People do not want us... we have to rely on each other. Most of us are not wanted by our family members because we are gay. It is difficult to explain our work to our family members... they will despise us. I had been living with my sister but I think she suspected my orientation and has put me out of her house.

We are also fed up with gay groups who keep using us to get donor funding... most of us did not go far in school. I dropped out of school in class two. We have to care for each other. I know everyone here knows Jeremiah. He refused to take ARVs, became very sick and was admitted at Kenyatta National Hospital. He died on Saturday and he did not have his people... we have to make arrangements to bury him... if you know you have been told to take ARVs, you better start...we do not want to bury any more of our colleagues.

Georgina follows Jemima, mentioning friends they have lost who refused to take treatment despite group support and ends with the declaration: “*We do not want to lose others when we have medicines available!*” Marian then turns to Kate, who they accuse of

throwing away his medicines: *"Our brother here started taking ARVs but he has stopped taking them...now it has been a year."* Kate tries to defend himself:

I was on ARVs but I kept missing to take them for days because of being drunk and working odd hours. Also the drugs were too many. I thought the drugs were not helping me. I spoke to the counselor and I was given Septrin and a multi-vitamin and advised to take ARVs when ready.

Jane: *See how he is thinking about it. We have lost Chidi because he refused to take drugs. Go to Liverpool VCT, talk to the counselor and you will be given ARVs. You can also go to SWOP (Sex Workers Organization Programme).*

Latifa: *When you work late you can bring an extra dose with you for emergency.*

Marian: *I do not want to be called to take someone to hospital or contribute toward funeral expenses when one has refused to take drugs. We have free ARVs and we should take them...if you do not have food you can ask us to support you. Some come to Freedom Corner and ask for alcohol when they have not eaten yet and are on drugs...then they say they did not take drugs because they do not have food. It is better you ask for a plate of food first and later alcohol. If you come to me and you have not eaten I will not buy alcohol for you.*

Sofia is then asked about another colleague who is sick and homeless. Sofia reports that he had washed "his patient," and given him his ARVs, and that he was sleeping when he left. The group quickly appoints three representatives to visit the patient and report back to the group, but Sofia objects, fearing neighbours will ostracize him if other MSM are seen visiting him. The group members decide to collect money to support Sofia's efforts instead.

Once this is settled, Georgina, Sofia and Marion take turns trying to convince the meeting facilitator to give them time to "share experiences," claiming that they are "wounded" and need to "be open" so that they can know their lives are not over. The facilitator promises to reserve time for "experience sharing" the following morning, and returns to the alcohol and substance abuse training agenda that had been interrupted

by Carol's outburst. Those who had become animated during the discussions about Carol, Kate and Sofia's patient withdraw again. Maggie continues sleeping next to me.

The following day, like other participants, I was eagerly waiting for experience sharing. When the training facilitator arrives, however, she highlights the main issues covered during the training session and then distributes evaluation forms. This does not go down well with the participants. One interrupts, telling the facilitator he is very disappointed that she overlooked their request. *"We are very disappointed because most of us are wounded, we go through a lot, and we need to talk about it."* The facilitator, seemingly eager to conclude the training, responds that no one had responded when she had asked if there were remaining issues to be discussed. Soon the APHIA-plus coordinator arrives and pays allowances to the participants before concluding the training. I leave together with the young men who invite me to join them at Freedom Corner, where they "share" their most recent experience of feeling used by development groups.

Extraordinary support

Two months after the APHIA-plus training, Norah arrived at Freedom Corner carrying a handbag. She sat down and took out a book with a list of members who had made contributions to help Maggie. As she went through the list, she reminded those who had not yet contributed. When she finished I asked her about Maggie, the same young man who had sat been sleeping next to me during the training. Norah told me that they had forced Maggie to go to the hospital. When he was discharged he chose to return to his mother in Mombasa to convalesce. The Freedom Corner group members had paid his hospital bill and continued to collect food money to send to Maggie's mother while she cared for him. Every week, each member contributed 20 Kenya Shillings (less than five cents) or more, which was sent by M-PESA (a mobile banking system) every month. This continued until Maggie had regained his health and returned to Nairobi. Fifteen months later, a healthy-looking Maggie served as the Master of Ceremonies at the 2012 Mr. Red Ribbon Gala, a camp beauty pageant for HIV positive men.

During the period we worked at Freedom Corner, we witnessed the revival of three other group members, including Maggie and Sofia's patient. Similar care was also

extended to other *kuchus* who were not Freedom Corner regulars, when their needs came to the attention of the group. In contrast, support systems across the city have collapsed, as once well-funded community-based initiatives have gone dormant in the wake of a global economic crisis that has led to a widespread divestment in HIV care. Whereas funding for antiretroviral treatment, condom distribution and formal support mechanisms are readily available to MSM sex workers, existing interventions have failed so far to recognize the everyday life challenges faced by these multiply marginalized men, resulting in their being alienated and excluded from the very programs that target them.

At Freedom Corner, male sex workers gather every evening as they prepare for the night in town, offering one another camaraderie, advice, and a degree of security in the midst of a hostile working world. They also encourage one another to adhere to their antiretroviral treatment and mobilize social support. In this case study, we have attempted to provide insight into the challenges these young men face and ways in which public health interventions unintentionally exclude those who are most at risk.

Reflecting on conversations and gossip at Freedom Corner

The boxed text above provides a case study of Freedom Corner that was condensed due to the publisher's word count limits. The case study illustrates the social context of Freedom Corner and provides an ethnographic account of a MSM sex worker training meant to encourage responsible sexual behaviour and the use of condoms, as well as the extent to which such interventions often fell short of the expressed needs of MSM sex workers. In the remainder of this chapter, I present further ethnographic insights gained from observations and informal conversations conducted at Freedom Corner and from interviews and focus groups held with the men who frequented it. The findings are roughly divided into two sections. The first focuses on sex, sex work, clients, and pleasure, all topics commonly discussed and often gossiped about at Freedom Corner. These topics are later linked to a broader discussion of HIV and other health risks, condom use, and HIV-status disclosure. The second section examines the psychic trauma I witnessed among the men, focussing on their frustrations, disappointments, and emotional states.

Sex, sex work, clients, and pleasure

Unlike in the health facility- based support groups where HIV prevention and treatment adherence dominated discussions, often in Freedom Corner space talks on being taken, sero-conversion, group sex, pimping and brokering, stamping, backstabbing and pleasure were dominant.

'Being taken'

The phrase 'being taken' refers to being chosen by a client, and most of the MSM sex workers at Freedom Corner were willing to do almost anything to improve their chances of being taken. Most had to work hard to compete for clients and sex work was their main source of income. Discussions on being taken often featured references to HIV disclosure and condom use. According to Sofia, 'disclosing one's HIV-positive status or initiating condom-use discussions with clients was *kumwaga unga* [literally, "wasting flour"; colloquial usage, blowing off an opportunity]. You will not be picked'. Similarly, Stella observed, 'What can you do? You are hungry, you need food, [you have] no place to sleep and you do not have money'.

Latifa recounted that after attending a couple of HIV behavioural intervention trainings, he felt he should protect one of his regular clients, so he suggested they go for HIV testing together. Latifa tested positive but the client was negative. As a result, the client left him. 'So you see, it is risky. You disclose and you lose a client'. Latifa, like many of the MSM at Freedom Corner, was well informed about HIV. He continued:

Before I was enrolled in different programs, I did not have any information on HIV. I did not know what was happening. But after I moved from Mombasa to Nairobi, I attended several trainings by SWOP, NASCOP, LVCT, and NPI. I have learnt a lot. I now understand how HIV is spread, opportunistic infections, adherence, STIs, re-infection of HIV if you do not use condoms. However, in many of my sexual encounters I do not use condoms. In a month, I may use a condom only once.

Despite his knowledge and claiming he feels bad about it, Latifa remembers his experience of losing an important client and does not disclose his HIV positive status to sex partners for fear of losing them. Like many in the group, he also does not mention condom use to clients: 'If you tell someone "we use a condom", they ask if you are sick. So it is better you keep quiet. I have no problem if clients request that we use a condom, but they do not'.

Latifa's decision to not even attempt to use condoms with clients obviously put them

at risk for HIV, but it also put him at risk for sexually transmitted infections (STIs). One day, Latifa showed me three syringes and medicines that he had been given at a clinic for STI treatment. He carried these around with him because he was homeless and had nowhere to store them. He complained that he had spent more money on treatment of STIs than what he earned from sex work.

It was common to hear people discuss being on STI treatment at Freedom Corner. For example, Jacklyn who identified as bisexual and was a peer educator, and thus was very likely as informed as Latifa, contracted an STI that led to hospitalization. When I visited him in hospital and asked him how he had contracted the STI, he only smiled. He died 5 months later. HIV and STIs were rarely discussed at Freedom Corner. When HIV and STIs were discussed, it was usually in the context of gossiping about people known or presumed to be sick or when there is a death. For example, it was known that Wambui, a sex worker in his mid-20s, was suffering from untreated genital warts. As his condition got worse, he developed had a foul odour and could not sit upright, yet he still sold sex. I asked another of the sex workers how Wambui could continue to engage in sex work. I was surprised but not shocked though when I was told, ‘in fact clients like warts because it holds their penises very well – they enjoy it’. He continued, as he demonstrated the grip with his hands, ‘warts grip the penis well, and that’s what clients want’.

Freedom corner group members talked about not mentioning condoms to their clients. Some group members shared how they were abandoned or rejected by their clients upon disclosure. Kate told how disclosure cost him a relationship with his long-time middle-class lover even though condoms had been used before:

When I began being sickly, my long-term partner asked me to go for a HIV test then share the results with him. He sounded very supportive. I tested HIV positive and took to him the results. That was the end of our relationship. Even though we always used condoms, he did not want to see me again.

Josephine and Clarice reported similar challenges when suggesting condom use or attempting disclosing their HIV-positive status to clients. ‘Sometimes you suggest to a client about condom use, and he will ask, “So you are sick?” As a result, you will not be taken again. So we keep off the issue of condoms and hide our HIV-positive status so that we maintain our clients’, said Josephine. Clarice continued: ‘I cannot negotiate condom use. Most clients do not want them. When you suggest using a condom, the clients will ask, “why?”... You cannot insist because they will think you are HIV positive and leave you’.

Fear of losing clients meant that despite high levels of knowledge and relatively easy access, the MSM sex workers at Freedom Corner rarely used condoms, which greatly restricting safer sex practices. One Friday evening, as I socialized with some of the MSM sex workers at Freedom Corner, four other study participants accompanied by three female sex workers in their mid-30s arrived. All wore red T-shirts and carried bags with them. As they took seats, they placed four boxes of condoms and three boxes of lubricants on the table. They told me they were SWOP peer educators and were coming from peer education training. As they settled in for drinks, I watched the lubricants quickly disappear into pockets and bags, but the four boxes of condoms remained untouched.

Sero-conversion

Closely related to condom use was the topic of sero-conversion, or becoming HIV infected while engaged in sex work. A story I heard several times, usually told amidst laughter, was of two MSM sex workers were HIV negative when they joined the group at Freedom Corner but who later became positive. Each had taken three successive HIV tests in a span of a year, and they tested negative each time. They had been given information about how to protect themselves from HIV infection. Despite this, they both tested positive the fourth time around. One said that it was poverty that pushed him to engage in unsafe sex, adding that he was going to eat well to maintain a high CD4 count to delay getting on ARVs.

In a focus group discussion, the sero-conversion of the two group members was blamed on alcohol, which led to them abandoning condom use within the context of a long-term relationship. All the participants admitted that they did not use condoms in long-term relationships, especially when they were drunk. Although some reported using protection at initial stages, they abandoned them when they got used to each other.

Group sex: more money, more risk

In addition to engaging in sex with individual clients, sex workers at Freedom Corner also engaged in and openly discussed or networked for group sex, a topic which I knew almost nothing about prior to my research. I first learned of it when I ran into Georgina one day around 5:15 in the evening at Freedom Corner. He seemed quite relaxed, drinking his favourite locally manufactured beer, called 'Euro'. When I asked him how his day was, he smiled and replied:

Good, I'm just from group sex with a female sex worker and a client. Everyone does it and it pays well – between KES 1,000 [€20] and KES 2,000 [€20] per person per session. Today I earned KES 1,500 [€15].

Responding to my inquiries about what this entailed and how it was negotiated, several sex workers who were present explained that it usually involved two or more sex workers (either male only or a mixture of male and female) and a male client and that a range of pairings and partner exchanges took place, often in one room or even one bed. Most clients actively participated in the sex, while a few would watch as sex workers had sex with one another. Watching served to stimulate erections; some clients would become erect as they watched group sex; some ejaculated without physically participating in sex; others rushed out to their female lovers once they became excited. Occasionally, a couple would also hire one sex worker to facilitate their group sex fantasy. One sex worker reported a male couple who were regular clients. When he was taken by them, he would be expected to perform oral sex and to be receptive to both during anal sex.

It was clear from the stories I heard about group sex that there were serious health risks involved. Both Carol and Sofia told me that condoms were never used during group sex: 'when you are taken for group sex, you do not discuss condoms'. However, according to those who participated in group sex, it was more economically advantageous than sex work with one client, and sex workers were not inclined to refuse it, especially when the market for regular sex work was performing badly. Not surprisingly, tensions and classes emerged when networking for group sex.

Pimping and brokering

Pimping or brokering was a business deal where people – often former or aging sex workers – arrange clients for a fee. Brokers were paid by former clients to arrange younger sex workers who were deemed 'fresh on the market'. Brokers sometimes brought clients for the Freedom Corner sex workers. Sofia told me that competition from younger MSM sex workers threatened the livelihood of older sex workers, making brokering an alternative source of income for older sex workers.

One of the advantages (from the perspective of clients) was that younger, 'fresh' recruits usually did not know the HIV status of clients or how to negotiate condoms (Sanders et al., 2007; Larmarange et al., 2010). According to some of the group members, brokers

routinely withheld information about the HIV status of their former clients from the new sex workers. As Jacinta put it:

Brokers do not tell the HIV status of the clients they hook you to. They are paid by the clients to get sex workers for them, so they know new sex workers may refuse HIV positive clients yet they [brokers] have taken the client's money. So they don't tell you about the client's HIV status.

Carol adds, 'Most new sex workers do not know they can get HIV from having sex with other men, they only know about women'. He makes his point via a personal story:

I was with Mary and we exchanged numbers. The following day he called and asked to meet me in town. He told me of a friend who would like us to do some work. We met this guy in a hotel room. He bought us drinks. Then Mary told me to have sex with this man who would then pay us well. I told him I had never had sex and I have never undressed before a stranger. He insisted and I told him he should undress first and show me how to do it. He did undress and had sex with the guy in my presence. I was then told it was my turn. We ended up having group sex. After three days, Mary took me to another client. For three months I was set up with different clients. Mary never told me about the HIV status of those clients and neither did he tell me about condom use. Later on, he told me to go for a HIV test. I tested positive. I do not know precisely when I contracted the virus.

Although brokerage was frowned upon and blamed for HIV infections among new MSM sex workers, brokers were never confronted. During a focus group discussion where one participant was a broker, the others accused him of pimping them out without disclosing his clients' HIV statuses. The pimp did not deny the accusations; instead he laughed and gave an account of his pimping activities and how he would later refer those he pimped to Liverpool VCT for HIV testing.

During another conversation, Sofia painted a slightly different story. She said that young sex workers ignored the advice of older sex workers in the name of competition: 'We have many young people who keep joining sex work. Clients like to take them. However, when you warn them to be careful, they instead think you are jealous of them because of competition'.

Stamping

Another topic commonly discussed at Freedom Corner was the practice of ‘stamping’, or intentionally infecting someone with HIV without their knowledge. The ‘stamper’ (one who intends to infect the other) conceals his HIV-positive status from the ‘stampee’ (who is targeted for HIV infection), whose HIV status is unknown. Those who were thought to be stampers were gossiped about. For example, people gossiped that Carol had stamped his long-term partner. Those who gossiped were convinced that Carol’s partner was HIV negative, and Carol did not disclose his HIV-positive status to him. It was widely known that Carol’s partner tested HIV positive months after entering into this relationship.

Desire for pleasure

Informal discussions about desire or expectation for sexual pleasure and affection were explicit and common at Freedom Corner. Such stories were told in a relaxed mood and were usually triggered by fantasizing about handsome men met during the day. They discussed how their desires for sexual pleasure remained elusive in sex work. For example, Latifa told me how sometimes he could be taken, thinking he was going to perform penetrative sex, which brings him pleasure, only to end up being receptive. On another occasion, a group of seven sex workers discussed a tall, dark client, apparently familiar to all of them, who had no issues when it came to payments but was only focused on his gratification:

Latifa: You know the dark tall guy?

Three others (chorus): Yes.

Latifa: You get to a room with him, you do what he wants, and soon as he ‘comes’ he dresses up, puts your money on the table, and walks out. Now you are done with sex and left alone wondering whether to sleep or walk out too, because the money has been paid, the client has finished his business, and left. You are left asking for more pleasure. (Chuckles)

Stella: Yes and he is not a difficult customer when it comes to payments. He will come in a taxi, stop, and ask you to get in. He then asks your name is, you tell him, and that is the end of the discussion. You get to the room, have sex, he dresses very fast, puts your money on the table, and leaves.

Group: (Laughter)

Latifa: You know most of the time we sell sex for money but sometimes your body just lusts for sex.

Researcher: But you have sex with your clients?

Latifa: For me it reaches a time when I just desire sex for pleasure. You feel the body just wants sex and I cannot hold it back. I must look for someone for sexual enjoyment. If I have the money I prefer to walk around town, identify some man, seduce them, and pay 200 or 300 for the service. If I do not have much money I would hook up with one of the sex workers, buy them beer, then we enjoy sex. And when I do not have money at all, I will go to my steady partner.

Only one of regulars from Freedom Corner ever reported experiencing pleasure from sex work. Joyce told me:

I sell sex to men who are older than me but I enjoy it better with younger men. And sometimes some men make me enjoy sex very much. I got a client from the Luhya tribe, I really enjoyed sex with him. He was so good that when he paid me I gave him change. I decided he was too good that I gave some of the money back to him.

In the words of Latifa, 'sometimes the body just lusts for pleasure'. Like their clients, pleasure came at a cost for MSM sex workers. In search of their own pleasure they told they used the money they made to pay for cheap lodgings and food so extra money could be used to pay for sex or buy drinks for colleagues they admired in exchange for sex. Some of them had long-term partners who they could call upon for pleasurable sex, while others enjoyed the company of their colleagues.

Backstabbing

Competition for clients could sometimes be very fierce at Freedom Corner. Given that most clients had no interest in hiring someone who was HIV positive, some sex workers would use their knowledge of other sex workers' HIV status to dissuade clients from choosing them. This practice of maliciously disclosing someone's HIV-positive status to his clients without their knowledge was referred to as 'backstabbing'.

I witnessed the after effects of backstabbing one evening when I met Carol sitting apart and alone on a bench at the entrance of bar that housed Freedom Corner. Responding to my query as to why he was sitting on his own he replied:

Kuchus are very bad people. Yesterday I had a date with my regular client at Simmers [a popular bar and restaurant in Nairobi's central business area]. Then I excused myself to go to the washrooms. On coming back on the table, he confronted me, [saying.] 'You have really

wronged me, why didn't you tell me that you were HIV positive?' He paid the bill and said he did not want to see me again. I'm very sure there was someone at the bar who told him about my HIV status when I went to the washrooms.

Emotionally wounded: (psycho)sociological issues

In the case study above, I wrote that my first encounter with this group was at an *APHIAPlus* behavioural training and that a question from the trainer about self-concept resulted in Carol crying. There was demand to have a session for sharing because, attendees said, 'people are wounded'. At the time, one of the MSM sex workers told me I should come to the next session with a counsellor, not for them but for me because I would not be able to handle the wounds they were going to share. From my perspective, it seemed they were simply asking for space to talk about the pains they were going through, something I had witnessed taking place in many of the other support groups I had attended. To me, it seemed that there was a clear relation between people being given the opportunity to process the psychological wounds associated with an HIV-positive diagnosis and people becoming empowered to make positive health-related decisions. But the *APHIAPlus* harm-reduction trainer avoided opening the space to discussing psychosocial issues, instead choosing to use the remaining seminar time to stress reduction of alcohol intake to enhance treatment adherence and the efficacy of ARVs. She asked the group to support each other in adhering to treatment, but failed to address the psychic wounds that – at least in my mind – were a key aspect of why they failed to adhere to treatment in the first place.

When I was invited to Freedom Corner I was eager to see how such wounds would be handled there. However, for all the good that Freedom Corner did for MSM sex workers who congregated there, it also was a place that could increase people's sense of hopelessness and powerlessness. Even as it did provide a space to air one's disappointments, the collective awareness of the difficulties faced by MSM sex workers, including almost certain HIV infection and limited opportunities to improve one's living circumstances, discussions often seemed to propagate a fatalistic attitude that likely contributed to risky sexual practices and the failure to adhere to medical treatments for HIV, STIs, and tuberculosis. In a context where 'backstabbing' and 'stamping' were common responses to competition for clients, it was common to encounter those at Freedom Corner expressing anger by shouting at each

other and loudly quarrelling. Without downplaying the important care and support work I observed at Freedom Corner, I must also recognize that members were often emotionally and psychologically distraught and, further, that their psychic wounds were often made worse as they grappled with the complex emotions they experienced as HIV-positive, homosexual sex workers.

Wounds that never heal: Carol's story

Although coming to grips with their sexual orientation presented serious challenges for many MSM, engaging in sex work and being HIV positive seemed to trigger many more negative emotions and resentment. Carol, who was relatively comfortable with his homosexual identity, was not at all happy about being HIV positive and a sex worker. Those were two identities that he did not want. Carol had two brothers and a mother who had been a sex worker. Carol and his brothers never knew their father(s) and when their mother died, Carol and his siblings were left in the care of their maternal grandmother who owned some rental properties in an informal settlement. Carol did very well in primary school and proceeded on to a provincial high school, but dropped out due to lack of money to pay school fees. Although his grandmother tried to reassure him, pointing out that she had not gone to school yet she owned rental properties, a less generous uncle told him that he would be like his mother – a ‘useless prostitute’. When I interviewed Carol, it was clear that his uncle’s proclamation lingered in his mind. It was a deep wound that had never healed and the fact that he did become a sex worker seemed to make it all the worse. Remembering his transition from promising student to sex worker, he recounted:

After dropping out of school I got a part-time job selling air time [cell phone minutes]. During one of the promotion activities, I was hooked up to sex work by a broker. The broker introduced me to many clients and three months later he told me to go for HIV testing. After testing positive I was introduced to other MSM sex workers. I really get enraged when I reflect on my uncle’s words, that I will be a prostitute like my mother. I never wanted to be a sex worker – I even did not know I was being introduced to sex work [chuckles and keep quiet for a long three minutes]. I have no problem with being gay, it is fashionable and classy, but I did not know I would be HIV positive and a sex worker.

Telling his life story clearly triggered complex emotions in him. He was angry and cried as he told me about dropping out of school and when remembering the words of his uncle. He

truly believed his life would have been better had he been able to continue his education. On another occasion he angrily told me:

I never thought I would be a sex worker in my life. Now I am a sex worker and HIV positive. I'm very useless. I'm a Christian, by the way, I believe in God. I used to be very active in church as an altar boy. Sometimes I do not understand what went wrong with me. I was very bright in school – sometimes I ask God why me, why am I suffering?

In my conversations with Jedida, I would notice that his moods always changed at the mention of being gay. Behind his smile, I could see tensions and struggles within. He told me that he admired working MSM, and saw them as classy and fashionable. Like Carol, he felt he could not match up to due to his poor education and poverty, and therefore had settled for a low-class life. For Jedida and many of the others at Freedom Corner, hopes for escape seemed tied to finding a wealthy, perhaps foreign, lover who would take them away from their lifestyle. Perhaps this is why my link to Amsterdam sometimes ignited their dreams and hopes. One afternoon as we walked, from the HOYMAS office in Pangani to Nairobi's central business district, Jedida told me about his dream to live a better life abroad. When I asked asking how he was going to realize this dream, he asked if I could invite him to Amsterdam. Jedida and Carol, like many others, seemed to have accepted a low-class life as their destiny. Yet, this did not diminish their desires to become or be loved by well-educated, well-groomed, gainfully employed gay men.

One evening Carol arrived at Freedom Corner accompanied by Cynthia, an MSM from Mombasa. As they took seats Carol gave me an envelope saying, 'I have received so many of these certificates but they don't help. I have ten of them, I thought with these certificates I would get a job, but they have not'. Carol and Cynthia had just completed certificate training at the Kenya AIDS Vaccine Initiative (KAVI). Carol also worked as peer educator at HOYMAS, which paid him a monthly allowance of KES 4,000 (€40). He also periodically worked as peer educator at the Sex Work Organization Programme (SWOP). Still, he was looking for a job that would pay him more and allow him to escape his low-class life. Carol explained how he had been short-changed at HOYMAS, detailing the recent rise of a key population mogul. They had started the organization together, but only Carol continued to languish in poverty. Here we see that Carol's experience with support-oriented NGOs is similar to those reported by people living in poor neighbourhoods in Kibera. Carol, however, was grateful for his involvement in internationally sponsored NGO interventions. His face brightened up when he talked about trips to South Africa and Amsterdam for conferences. He

relished the admiration he got from his brothers for travelling abroad; however, his economic expectations were not met.

In one conversation, Carol lamented a lack of role models at Freedom Corner. He told me that he lacked role models to show him how to escape his low-class life and poverty, saying that income from sex work did not 'stay'. Neither was it put into personal development. Instead the money from sex work was spent on alcohol, *khat*, and paying for sex for pleasure. Carol said:

Someone gets some good money, and they *chafua meza* [literally, dirty the table (with bottles); colloquially, buy a lot of beer for one's friends]. There are those older sex workers who tell us how they got a lot of money but all went on alcohol and buying sex.

Similarly, Sofia told me he had made a lot of money from sex work, but had nothing to show for it. He had a rich long-term partner who rented him a house in Zanzibar. Although Sofia does not drink alcohol, he spent his money entertaining his friends. At the time of the study, Sophia was homeless, living in a makeshift structure in one of Nairobi's forests.

Group dilemma

Ironically, Carol was known to be one of the heaviest drinkers in the group. Despite becoming progressively disheartened over the time I knew him, he continued his life and his affiliations with Freedom Corner. On several occasions, I asked Carol if he considered stepping away from this group, which he defined as hopeless and low-life. He replied, 'This is the only group that understands me. We have some good people among them. When I have a problem I talk to them and they help me. If I drop out, who will help me? Who will understand what I'm going through?'

However, given Carol's state, they could only understand so much. I am certain Carol was frustrated that the group could not understand his psychic wounds and the inner demons he was battling. The other group members were often frustrated with him; they did not understand the underlying issues that contributed to Carol's non-adherence to treatment for HIV and tuberculosis. Midway through my study, Carol stopped treatment for both diseases altogether. He told me he was being stigmatized. But group members said they were worried he was not taking his TB medicines and they feared contracting the disease from him.

Shortly after, Carol disappeared from Freedom Corner. True to the spirit of 'my brother's keeper', his fellow *kuchus* got worried and looked for him. They called me for an urgent meeting to discuss Carol's condition. Before the meeting, I had a discussion with Carol who expressed his disappointment with life. Carol repeated the same words he used the

first time I met him at the *AphiaPlus* training: 'My life is wasted'. He added, 'these people [Freedom Corner group members] do not understand', and repeated again the words of his uncle, 'you will be a prostitute like your mother'. Finally he told me that his life was very difficult because he did not have money and that he could not take medicines without food.

When I arrived for the meeting, the members expressed disappointment with Carol for stopping medication. It was clear this was not the first time this had happened. They told me that he had abandoned medications several times and ended up being carried to hospital when he was very ill. They explained how they kept taking him in and nursed him, making sure he took medicines, but upon improvement he always stopped taking his medicines. 'Carol, we cannot help, if you don't want to be helped', one of them said. They accused him of not taking his life seriously and preferring drinking to taking medicines.

Through my contacts with peer mentors at Kenyatta National Hospital, I was able to get Carol reinitiated on TB treatment and get him access to ARVs. Eventually he began to put on weight. I returned to Amsterdam for a year but continued to get updates about him, and I was assured he had greatly improved. Upon my return I was surprised. Contrary to what I expected, Carol had lost a lot of weight and he was homeless. I pushed the HOYMAS director to get him a house, food, and a few household items. Three days later, I got a call from his partner that Carol was very sick. He was admitted to the hospital and when I visited him, he confessed that when he got treated for TB he stopped taking ARVs. Again, together with the HOYMAS director, we made efforts to reinitiate him on ARVs.

Three months later, I got a text message from Carol requesting that I see him urgently. The text read, 'I am at the rescue center. I am on medication but the body is not responding well. I have food but I don't have anyone to talk to'. I visited the rescue centre and found Carol with two other MSM sex workers who had also been admitted. We talked about the healing process. I encouraged him to stick to the treatment regime.

Four months later, I got a distress call from Carol asking me again to see him right away. He had been admitted to a hospital in Kiambu County. By then I was working in Mombasa. I got information from his colleagues that he had developed multi-drug resistant (MDR) TB and was in an isolation ward. I later got a text message from him saying, 'please come and see me'. The next day I received a call at 5:00 in the morning from one of his friends; Carol had died.

Even without a psychology degree, it was clear to me that Carol was deeply and psychically wounded. He exhibited ups and downs, but was regularly depressed. He traced

his own wounds to his childhood, but it was clear that his HIV-positive status and his engagement in sex work only made his wounds worse. Despite the considerable social, economic, and emotional support he received from his brothers at Freedom Corner, he was unable to remain motivated enough to take his medications and save his own life. In my engagements with him I witnessed his emotional pain, ambivalence, feelings of hopelessness, and the irreconcilable intense internal conflict and tainted self-esteem that led to deep resentment. He was incredibly sad and angry, in an unstable state of mind. His wounds were not healed.

Longing for acceptance at Freedom Corner: Georgina's story

Georgina, the person at Freedom Corner who first told me about group sex, liked to tell me about his family, and especially about his mother, his separation from his wife, and his child. On the day he opened my eyes to group sex, he was in a good mood because he had just earned 1500 KES. He ordered a drink for me, which was normal practice when *kuchus* had money; they would buy drinks for everyone at Freedom Corner. After telling me about group sex he went on talking.

As he began talking about how he had become a sex worker, I noticed his mood shifting, the psychic wounds he harboured over years becoming visible. His mood swung up and down as he talked. One moment he was all smiles, the next moment he was very angry, shouting at the top of his voice. He was so angry that I began to worry he would attract unwanted attention, yet I wanted to hear him out, if nothing else than for the sake of the study. He told me he was devastated when his wife had left him and took away everything in the house, including his lovely fridge and their only daughter. He had left his house in Naivasha for Nairobi. In Nairobi, while having lunch in a restaurant, a man seduced him. His face brightened up: 'I felt, wow! You mean I can be attractive to a man!' recounted Georgina with an approving smile. Out of curiosity he went out with the man and they became good lovers. He went out for a while with the man, and later at the same restaurant he met Kate, a fellow MSM sex worker, who became his friend and introduced him to the *kuchus* who would eventually start meeting at Freedom Corner. As the conversation continued, he became very angry again, this time with his stepfather.

My stepfather really hates me. I hate him. He heard rumours that I was gay but could not confront me directly. Instead he told his sisters who later told my mother. My mother asked

me about it. I denied the allegations. [He smiles and continues.] Then she told me, 'You are my son, if you are gay you are still my son, but I pray that God can change you back to what you were before'. I did not own up, but when I got money I went to see my mother and explained to her. She accepted me and I am really proud of her. She really supports me. I send her money when I have it and likewise she sends me money when I do not. [He frowns and gets angry.] But my stepfather sees me as useless. I'm very angry with him... I want him to apologize to me because he should have asked me if I was gay first before telling his sisters.

Georgina is proud of his mother even though he acknowledges that she does not fully approve of his sexual orientation. Although she hopes her son will one day return to what he was before (a heterosexual married man) and have children, for the time being she is standing with him, and even financially supporting him.

Similar to Georgina, most of the *kuchus* at Freedom Corner longed for others, especially their families, to accept their sexual orientation. They were disheartened by the constant disapproval they encountered. Such situations exacerbate the psychic wounds that most of the men at Freedom Corner carried.

Homosexuality, masculinity, and fatherhood

As we see with Georgina, in many ways, one of the hardest things to accept for relatives of homosexual sons is the idea that their sons will not father children. In Kenya, as in most places in Africa, one can only be considered a man when one has fathered a child. Until then, friends and family will continue to call you '*kijana*', meaning youth, or even boy. This is how the priest justified the final emasculation of Carol when he declared that Carol would not be buried as a man. The Catholics could not bury him as a Catholic and the Kikuyus could not bury him as a Kikuyu man.

Fathering children is considered an important aspect of being a man in Kenya, and this is no less so for homosexual men. They could not reconcile kinship and homosexuality, especially on the issue of fatherhood. One evening at Freedom Corner I started a conversation with Kathy who often discussed his family with me. I enquired if he had visited his mother recently, as I knew she lived nearby, only 15 kilometres from Nairobi's central business district. Kathy said he had not been home for a year because his mother kept asking him about marriage and children. He told me he was considering a novel solution: 'To make peace with my mother I have been thinking of entering into a marriage deal with a female sex

worker whom I will take to stay in my home and bear a child'. Not challenging his proposal, the other *kuchus* told Kate to get a female sex worker who was also HIV positive. Once they finished planning Kate's fantasy wedding, they began discussing 'being a man'. 'As a man, in my community, I must marry and have a child', observed one. Two others concurred, as he continued, 'A wife, children, and a home is what makes a man, and as a Luhya man, this is what my community demands of me'.

These reflections on masculinity reminded me of a conversation I had with Sofia, who had left his home in 1982 and has never been back. Sofia told me:

In 1982, a day before the attempted military coup in Kenya, my mother sent me to my uncle in Nairobi to collect school fees. I got to Nairobi on the morning of the coup. It was a chilling experience. There were no vehicles. I met a man who offered to give me a lift to Kawangware where my uncle lived. Instead he took me to his house and asked if we could have sex for a fee. I agreed because I had sexual attraction towards men. I ended up staying with this man for a week. I did not go to my uncle's place. Instead I went back home and gave most of the money I had made from this man to my mother. I did not want to go back to school because I had found a nice way of making money. I travelled back to Nairobi and went straight to this man's house. We had sex and he paid. With time he would bring me other clients, many clients. Then one of my clients told me I was not being paid well, and introduced me the lucrative market for sex work. Since 1982, I have never gone back home. I fear if I go there, people will ask me about my wife and children. I'm now growing old. I will retire from sex work. I do not plan to retire and go back to my village; I will look for something else to do.

Sofia has not been in touch with his relatives for over 30 years. His case is not unique though. Fear of disapproval for failing socio-cultural expectations has kept him away. Not having a wife and children seemed a major concern for *kuchus* because of the dominant notions of heterosexual masculinity (Brown, Sorrell & Rafaelli, 2005; Campbell & Williams, 1992).

I joined in the funeral preparation activities, fundraising and burial of Carol. This was the only burial for *kuchu* I attended. I was told that more than 200,000 KES (2,000 Euros) was raised. Apart from the Freedom Corner group members, members of HOYMAS, other MSM and sex worker-led organizations, we were joined by other MSM sex workers and even donor organizations. Those in the burial entourage were told to dress well- nothing suggesting MSM or sex work. My *Kuchu* friends were smartly dressed. As we set off for the burial, we were alerted about tension among people in Carol's village- the place for the burial. To avoid societal violent reactions, we were told to behave well: no wailing or doing

anything that would publicly expose an MSM identity. We arrived at his home area in a convoy of over 30 vehicles, including a bus and van. Carol's, uncle told the mourners; "Carol neither had a wife nor a child [] he has left us with nothing other than painful memories". Carol was a Catholic. During his burial the priest presiding over the funeral service noted that he could not allow Carol's body to be taken to church, and also could not offer him full mass service at the burial site because he had not received any communication from any Catholic church in Nairobi to show Carol was a practicing Catholic. The priest added that at 28 years old Carol should be buried as a man, but he was not going to be because he neither had a wife nor a child. As a final rejection of his way of life, the priest decided that Carol was going to be buried as a boy.

At first I assumed such tensions only existed for those without children and who had never been married to a woman. On hearing the story of Betty, a 43-year-old I had assumed was bisexual, I learned differently. He explained:

I got married before I realized that I was sexually attracted to men. I was very faithful to my wife and we had three children. Then I started getting attracted to men. The desire became very real till I had my first sexual encounter with a man. How do I live with my wife when I am sexually attracted to other men and not her? My major concerns have been how my children and society would behave towards me if they got to know about it.

Betty realized he was gay several years into a heterosexual marriage and after having children. One would think that he had escaped the worries by marrying and fathering. But he worried about breaking away from living a lie. Living a discreet homosexual life was psychologically damaging to Betty. He was known in the community as a heterosexual husband and father, and his major problem was how to undo the lie. Eventually, his wife did come to know about his homosexuality. He ended up leaving and preferred to stay in seclusion with his problems. Unfortunately, he died five months later.

Conclusion

In this chapter I have attempted to sketch a picture of the complex social, cultural, economic, health, and psychological issues that confront male sex workers in Nairobi at a time when there is a great deal of international funding available to motivate them to wear condoms, disclose their HIV status, and take antiretroviral medications. Following the men from

Freedom Corner, I would argue that this funding is not really intended to improve the lives of male sex workers in any significant way. They argue that the NGOs need them – they are bio-valuable – in order to keep the funding stream flowing. There is probably some truth to this, but the key population interventions I have observed were clearly much more focused on promoting pharmaceutical treatment of HIV than on providing psychosocial support to those living the most marginal lives in Kenya: MSM, sex workers, and injecting drug users. The support groups they run are stripped down to the bare essentials. There is little space for the sharing or healing of psychic wounds. At the same time, organizations like HOYMAS, which was co-founded by Carol with input of several other members of Freedom Corner, are moving the way of so many grassroots NGOs in Kenya. Carol's critique was that he had been pushed aside by the current leader because he was not educated and because others in leadership had become greedy. While Carol and the other male sex workers could be called upon for demonstrations and TV appearances – their gender non-conforming dress and manners made for great spectacle – they were not sophisticated enough to become the face of homosexuality in Kenya.

I have attempted to show how the aims of key population interventions are often at odds with the self-defined needs of the men who are targeted. Drawing on an in-depth case study of male sex workers at Freedom Corner, I have highlighted the multiple ways that sex work puts men at great risk of HIV and other STIs, police violence, and psychological traumas associated with family and societal and state-sanctioned stigma and discrimination toward people with HIV, homosexual men, and sex workers.

HIV is a challenge to live with in a stigma-consumed society, and so are homosexuality and sex work. There are two schools of thought about how to intervene to support HIV-positive MSM sex workers: first, from the perspective of key population interventions, is the belief that support groups should focus on HIV prevention and promoting treatment adherence. In contrast, from the perspective of the *kuchus*, is the belief that support groups should focus on social support (nursing care, offsetting hospital bills), economic survival, sexuality, and human rights. The perspective of the male sex workers was certainly shaped by the multiple global health and human rights interventions to which they were subjected, but it was also shaped by their individual and collective experience of living what Carol called a 'low-class life'. If people working in key populations interventions were disappointed by male sex workers' expectations that they should be remunerated for showing up to a support group or a training, those at Freedom Corner were equally disappointed by the

extent to which the interventions failed to address wounds caused by ongoing economic struggle and psychological traumas.

Freedom Corner was a space where male sex workers resisted HIV interventions, while they strategized about the best way to leverage their (bio) value for economic gains. The Freedom Corner group provided inspiring social support but was also limited by the members' busy schedules, a lack of role models, and a lack of psychosocial expertise. While the group often responded well to health, housing, and legal crises, they were less equipped to address the emotional scars that so many of them carried with them or the day-to-day discrimination they faced on the streets, in the media, and not only from their families but also from better educated and employed MSM, many of whom were their clients.

CHAPTER 8

CONCLUSION

You do not understand!

It is 2:30 p.m. The Kesho Bora study clinic (my previous research engagement) at KNH is closed. The study participants have left, and a few members of staff are left to clean up for the day. My friend Camilla – a peer counsellor in the Kesho Bora trial – and I leave for the day. Together, we walk to the bus stop to catch a *matatu* (a local public means of transport) to Nairobi's central business district. We come across a group of eight Kesho Bora trial participants walking together to also catch *matatus* on Ngong Road. The Kesho Bora participants – all women – are carrying their children on their backs and six tins each of formula milk (provided free by the trial) on their heads. We bid farewell to the women as we continue with our journey. Soon after passing the women Camilla makes a profound observation: 'These women are going through a lot, and no one can understand'.

As we approach the first bus stop, Camilla suggests we walk to the next one and I comply. During the ten-minute walk Camilla, who is HIV positive, shares with me her experience with the inconsistency of her six-year-old daughter's HIV test results:

You know I have been having issues with HIV test results of my daughter. The first time it was negative. The second time I expected [it to be] negative but I was told, 'it is positive'. I thought there was a problem with the test. I told the counsellor, 'I will repeat the test'. Again, positive. I sat quietly, lost in thoughts. After everything I did to prevent infecting my daughter – my CD4 was still high, I took AZT [ARVs], delivered in hospital, and I exclusively formula fed – it really hit me. I cried. I did not want anyone to talk to me. I was very angry. The nurse counsellor dared to tell me, 'I understand what you are going through'. 'What!' I responded. She said, 'I know what you are going through'. I replied, 'Do you? Do you understand! You cannot understand... How can you tell me you know or understand what I am going through? Just tell me you can only imagine!' If you are not going through a similar experience you cannot tell anyone you know or understand what they are going through, you can only imagine!

I was challenged by the ambivalence around concepts of 'understanding', 'knowing', and 'imagining'. Yet I felt obligated to peddle hope when my research participants poured out heartbreaking stories to me. For instance, how was I to understand or know what Imma was going through: one moment she depressed and crying because her CD4 count had dropped

low and she would be initiated on the ‘dreaded’ ARVs, and she told me, ‘you do not understand’. The next moment she was texting, telling me she wants to have a baby. How was I to understand such shifting dramatic moments?

How would I understand Carol’s (chapter 7) shifting feeling and perspectives: one moment he does not like the support group, and the next moment he says this is the only group that understands him or the only people that he can relate to. It was difficult for me to understand.

Living with HIV, even in times of treatment, is traumatic and stressful. Narratives about life before support groups contained descriptions of social phobia, anger, guilt, rejection or social distance, low self-esteem, stigma, hopelessness, helplessness, and depression (Kyakuwa, 2009; Mello et al., 2009; Zhou, 2007; Burgoyne & Saunders, 2000). PLHIV may need others like them. ‘If you are not infected you will never understand what PLHIV go through’ was the mantra in support groups whenever group members shared emotions. Similarly, a KNH peer mentor told me, ‘You will never understand the pain going on inside PLHIV. You do not understand the dilemma they are going through. The world changes with HIV. It is often difficult to describe to those who are not living with HIV what life is like when HIV-positive. Therefore, it is only PLHIV who understand what each other is going through’.

Living with HIV, a condition that is surrounded by moral discourses, is complex. ‘No one likes to be HIV positive – even me’, observed a facilitator of community-based support group in Kibera, as he concluded a session in which most of the members shared, for the first time, their experiences with stigma and other challenges. At this, after an awkward minute of silence, one of the group members, a 25-year-old man noted:

Being] HIV positive is not something to be happy about or talk about. It brings about shame – you are despised, isolated – and it has many challenges. You have to rely on treatment every day without fail, there are fears of side effects and resistance: you must take medicines and eat, otherwise you get weak, and you have to be careful not to get infections otherwise you spend all your money on treatment of opportunistic infections. Most of us here economically rely on ourselves and sometimes, since we are seen not to be ‘sick’ [due to improved physical health from the medicines], our extended families back in rural areas expect money from us. For someone not married like me I have issues with relationships, particularly being intimate with girls.

HIV is a figurative prison that PLHIV are locked in punctuated by uncertainties and choices. In their quest to achieve a near-normal life, PLHIV, in different ways, are faced with a number of needs and challenges. While HIV treatment prolongs and improves lives, it does not eliminate care and support needs. For Camilla and many study participants, living with HIV was a daily challenge that PLHIV tussle with in various ways. Among the top issues on the list is the persistence of stigma, uncertainties about the future, social support, social and sexual relational battles, reproduction, practical needs, and re-integration back into society. PLHIV are compelled to depend on others (Odiwuor, 2000). They need social support or to learn from others how to cope with HIV. Within the notion that it is good to do things together, HIV support groups are a space where care and support is given and taken, PLHIV make social contacts, and learn from each other how to cope with HIV and develop self-care skills. Support groups are 'voluntary' social collective entities where PLHIV who feel they can benefit participate. Such groups should do something to help individuals develop coping mechanisms. Support group tool is a significant player that should be taken seriously.

In this study social relations around HIV is shaped by HIV status, gender, class, sexual orientations, biomedical interventions, public health (epidemiology) and HIV aid or funding. HIV-positive status is fundamental in the development of new social relations around HIV. The groups are a necessary resource in HIV interventions, without which it would have been difficult to mobilize people living with HIV. An intersection of factors motivates PLHIV's participation in PLHIV in support groups. They may have a variety of motivations, which often shift with the ever-changing needs and expectations of members as well as external factors such as funding, policies, and biomedical innovations. HIV support groups help those who participate in them to deal with issues that brought them to these groups and, thus, provide a window to examine the organization of care and support. It also provides a window to examine to observe technologically supported lifestyles and the implications of science.

This study set to examine the emergence, evolution, and implications of HIV support groups in the care of, and support for, PLHIV in Kenya. The question of how care and support are defined, and how support groups are imagined and utilized by PLHIV and other stakeholders, has been explored. I have attempted to outline different dimensions, functions, and implications of HIV support groups, taking into account the relationship between PLHIV and the groups.

HIV support groups may be studied as a one-time phenomenon, but cannot be understood except in terms of grounding in historical perspective. Using a historical perspective to HIV support groups in Kenya was very important. It helped in understanding the significance of various players and contexts in shaping and influencing groups, and reveals dynamism and political economy of HIV support group phenomenon. What was significant to this study was how HIV reorganized care and support, and how PLHIV engaged with support groups in relation to their care and support. Through ethnographic materials involving participant observations, numerous conversations, walking sessions, key informant interviews, in depth interviews, and case histories, I have examined closely how PLHIV relate to support groups, and the specificities of the functions of these groups in their contribution to care and support for PLHIV. While from the conception of this study I recognized contrasting socioeconomic classes to be central, inclusion of the middle and upper income populations remained marginal as explained in chapter 1.

There are important differences and specificities among support groups, as groups were formed for different functions and for different needs in time and space. The multidimensional nature of community makes support group space a dynamic arena with distinct players, the stakeholders. It is an arena where, by coming together, PLHIV are able to identify problems and challenges they face, define what it means to live with HIV, and therefore identify and define care and support and its delivery. It is an arena where shifting needs and PLHIV agency are contested. There is also a tendency to form support groups to respond to anything. It is also an arena where, 'unbeknownst to many members of the groups, fundamental issues of medicine and health and the responsibilities of health care system are being contested' (Kickbusch & Hatch, 1983, p. 193). It is also an arena where international and local NGOs play a key role as intermediaries who obtain the necessary financial and material support for PLHIV through support group. All the stakeholders in the arena are responsible for the multiplication and diversification of these groups. In this arena, community-based support groups enjoy flexibility, dynamism and diversity more than health-facility based support groups.

HIV moguls, in the words of Vito Russo (1988), are an example of that brave group of people, despite their shortcomings, who stood up and fought and even died for others to live. They are an important part of the HIV history in Kenya at a time when the government postures of neglecting participation and troubling societal stigma were obvious. And so is the importance of HIV support groups, which they pioneered. From the 1980s through the mid-2000s, the main

function of HIV support groups was home-based care (nursing care) and psychosocial support (mainly compassionate or emotional support). The emerging local economy of the civil societies can be traced to this period. During the HIV crisis era, between 2001 and 2009, the groups, as a new social institution that seemed to hijack the traditional social support system, stood out as a social force and magnet for HIV funding and interventions. The main function of support groups was resurrecting lives. Under the clamour for MIPA (Meaningful Involvement of People with AIDS) and GIPA (Greater Involvement of People with AIDS), the participation of PLHIV in HIV interventions was elevated. In addition to home-based care and psychosocial support, the functions of support groups transformed to HIV pragmatism and the mitigation of socioeconomic effects of HIV. This resulted in the development of a local economy of civil societies or NGO-ization, certainly changing the perception of PLHIV about the functions of HIV support groups.

The shifting terrain of support groups is also reflected in its objectives, functions and funding as well as the changing face of AIDS. This reveals the precarious nature of support group. The lack of cure, and continued shifting needs and challenges, highlight the resilience of these groups despite the drying up of funding and explaining group members' preoccupation with other economic survival activities given their improved health.

I have shown how HIV funding that accompanied HIV treatment resulted in a significant multiplication of support groups and NGOs targeting low income population, and it marginality middle and upper class. The funding or material support raised expectations of PLHIV and the groups became entrenched in the notions of dynamism, diversity, and transformations. For instance, among the HIV moguls and Kibera residents, the hype of participation manifested in the economic and material functions of the groups more than psychosocial support. The new class of moguls which emerged due to HIV funding came with tensions and conflicts, shifting functions, transformation of support groups, and a fragmented field that became obvious resulting in 'city-hopping' from one support group to another in search of care and support.

Psychosocial support became secondary in community-based support groups while it flourished in health-facility based support groups. Among the HIV moguls and PLHIV in Kibera, with HIV funding, support groups came to be viewed more as spaces for opportunities for amassing wealth and *msaada*. There is a tendency to see this as peculiar to HIV, but any funding or *msaada* is seen as an opportunity for individual benefit especially where corruption and poverty thrives. For PLHIV support groups in Kibera, the means of

survival hides in *msaada*. The search for *msaada* among people at the edge of the society became core, while in facility-based groups better biomedical outcomes, psychosocial support, and cultivating responsible PLHIV were core.

The transformation from the HIV crises era to the treatment era charged facility-based support groups with responsabilizing PLHIV to adhere to treatment and to prevent HIV infection. On the other hand, community-based groups focused on the economic emancipation of PLHIV through income-generating activities. This does not mean there was no responsabilization in community-based support groups. This was taken care of through treatment literacy sessions (for example by MSF and HAKI CBO in Kibera). In part, this accounted for the tendency to see support groups as spaces of support. Also at this time, when the responsibilities of caring and supporting PLHIV seemed to revert back to kin, it is clear that PLHIV turned to support groups for care and support functions that were not found within the traditional care and support system. These included, for instance, psychosocial, sexual, and reproductive care and support for PLHIV.

In the post-treatment era, support groups experienced the drying up of HIV funding. Key populations, in this case, men who have sex with men, sex workers, and people who inject drugs, became the priority for funding. From the public health perspective these key populations matter in the war against HIV, in terms of stopping new infections despite legal and societal constraints. The HIV intervention programmes that focus on access to HIV services, risk behaviours, and entrenching responsibility, however, overlooked the overarching functioning and wants of these populations. In chapter seven I showed the emergence of social relations and institution around HIV, MSM, and sex work. Behavioural change trainings targeting MSM sex workers became a springboard for the emergence of an organic support group that provided space for MSM sex workers to forge social relations, increase their visibility, and call attention to their human rights.

I have also highlighted the resilience of a few support groups in the post-treatment era. Some support groups and local HIV organizations diversified to deal with emerging issues confronting PLHIV. Other support groups went dormant only to become resurrected when need arises. What emerges, if there is anything peculiar about HIV support groups, is the way they are being fashioned to correspond to shifting individual needs of PLHIV as they live longer, for example dealing with sexual issues, sexual identities, and gender. Caring and supporting went beyond the types of nursing activities associated with HIV care. Following Rhine (2009), this study recognizes the possibilities of support groups in the post-treatment

era expanding from cultivating responsible patients, in treatment adherence and HIV prevention, to dealing with what has been avoided in HIV interventions: sexuality, masculinity, human rights, reproduction, and social reintegration.

Implications of HIV support groups for PLHIV

HIV support groups hold different meanings and play different roles exemplified by varied types of care and support. For both the individual and science, support groups have wide-ranging implications in the care and support for PLHIV. As biomedical innovations and interventions, these groups have implications in treatment adherence, improvement in the quality of life, and HIV prevention. This is as a result of support groups' promotion of patients' sense of responsibility through advocating 'living positively'. I have also raised herein some implications with regards to benefits and problematic relationship between the individual and the support groups. While reactions to HIV-positive diagnosis varied with time and space, the general narratives of PLHIV could be summed up in three words: anger, despair, and desire. Anger and despair for being HIV positive, and desire for father- and motherhood, love, normality, caring about and support. To PLHIV, the support groups have far reaching implications, especially in the context of their contribution to economic or material support, psychological or emotional support, resources, treatment research, health improvement, treatment adherence, nursing care, and social and informational benefits (Kyakuwa, 2012; Liamputtong et al., 2009; Heyer et al., 2010; Oosterhoff, 2008; T. Nguyen, 2005; Visser et al., 2005; Johnson, 2000; Tsisis, 2000; Kalichman et al., 1996).

Through the care and support logics of support groups there are benefits PLHIV recognize and attribute to their prolonged lives. While 'second lives' may be attributed to HIV treatment, support groups play a significant role in the lives of PLHIV, from pre-treatment time to the post-treatment era. PLHIV see support groups as an important step in adopting coping skills that were essential to improvement of health. In addition to one-on-one treatment adherence counselling sessions and treatment literacy, sharing experiences with treatment in support groups is also important in reinforcing coping skills. Delivering HIV information, psychosocial support, and social support (material or economic, nursing care) and propagating notions of living positively are ways that groups give PLHIV back their lives.

Psychological and emotional reprieve

The HIV support groups are an important platform for psychosocial care. The psychological effects of HIV constitute perhaps the most enduring issue confronting PLHIV. HIV-positive status brings about an emotional and psychological disorientation. PLHIV need psychosocial buffers. From the very beginning support groups in Kenya were conceived and fashioned for psychosocial support. Stigma and discrimination combined with finding oneself with a life-threatening condition, and pushed PLHIV to seek emotional support and hope from one other. The community- and health facility-based groups were anchored in psychosocial support, specifically companionate or emotional support. Psychological and emotional stressors are not limited to the moment of HIV diagnosis, and therefore were an enduring theme of HIV support groups. Often, people come to support groups and disappear, only to come back with follow-on needs and challenges, such as uncertainties about the future, management of HIV, side effects, lack of cure, disclosure and/or the lack of it, persistent stigma, worries about the CD4 count and viral load, sexual and reproductive lives, practical needs, and changes in social lives, sexual practices, reproduction, and sometimes lifestyles (Mayor, 2013; Marsland, 2012; Whyte et al., 2004; Hardon et al., 2012; Le Marcis, 2013). The need for psychosocial support is predicated on these factors, and, thus, reveal the significance of these groups to PLHIV.

Meeting with other PLHIV and sharing their experiences in support groups brings about feelings of relief, of not being alone, and of acceptance. Furthermore, support groups helped members recognize and re-evaluate their negative thinking, alter their thought patterns, and make changes to transition their lives. PLHIV in support groups acknowledged that psychosocial support had given them a second chance to live because of its role in improving their outlook on their lives and future. The groups helped them to move from anger, fear of side effects, feelings of shame, guilt, helplessness, hopelessness, despair, depression, anxiety, denial, and isolation to adopting coping skills or strategies, mainly acceptance of HIV positive status and treatment, treatment adherence, and future hope.

In the KNH support groups, psychosocial support was perhaps the most prominent function, often tailored to respond to specific issues that brought about psychological distress. The fact that the psychological aspect was not core in community-based support groups does not however imply that PLHIV who participate in those groups did not experience HIV-related psychological issues. They definitely did in varied ways. While psychosocial support,

as advanced by MSF Belgium, was important, so too was the need for food. For PLHIV in Kibera, practical needs were a source of psychological stress, and, in part, *msaada* was a solution. PLHIV from Kibera city-hopped to KNH support groups for what they did not gain from support groups focused on material support. For instance, men with sexual dysfunction city-hopped to KNH support groups. MSM sex workers, on the other hand, even with immense psychological distress, lacked space and skills for psychological reprieve.

Information and health implications

HIV information was aimed at producing ‘a competent community’, meaning informed and responsible members. This study has shown how HIV support groups have become increasingly instrumentalised via medical interventions. From the very beginning of HIV, PLHIV sought out HIV information from support groups. In the HIV treatment era, biomedical interventions rely on facility-based HIV support groups, while community support groups may pay less attention to HIV information, as they get the information from treatment literacy training and behavioral change training by the civil society organizations. Although information can today be found online or on social media for those PLHIV who have Internet access, PLHIV in KNH support groups relied on the support groups for information. Even the health providers in the KNH health workers’ group, who by virtue of their careers should be knowledgeable about HIV, acknowledged the informational value of support groups. PLHIV from Kibera, where HIV information was lacking in support groups, city-hopped to KNH for information.

Such information included basic facts on HIV (transmission, progression), prevention (safe sex or condom use, disclosure, PMTCT, and family planning), treatment (regimen, adherence, and side effects), and positive living (nutrition, safe sex and sexual pleasure, and behavioral change). HIV information mitigated myth and misconceptions, denial, fears of side effects, and psychological stress, and played a critical role in accepting HIV status and adopting coping skills. The information strengthened living positively by contributing to treatment adherence, disclosure, management of opportunistic infections, increased utilization of health services, self-care, and invigorated sexual lives and reproductive desires. For instance, learning about the CD4 count, viral load, and PMTCT helped in decision making on reproduction.

Economic/material implications

In treatment era, support groups served as an important platform for survival and economic opportunities. HIV creates economic vulnerability (Marsland, 2012), at the same time offers opportunities. Money and material support are critical in the lives of PLHIV. PLHIV leveraged their (bio) value for survival or economic gains. Support groups promised economic empowerment in different ways. Being able to earn money through providing testimonials, and organizing other HIV funding and support groups' economic ventures produced HIV moguls. Through support groups, a few other PLHIV got job opportunities that improved their economic status.

With the massive HIV funding, a clear material meaning of support groups could be discerned among PLHIV in low-income populations. It helped meet practical needs, especially food, rent and school fees for children and kept the groups going as to function effectively the support groups needed financial or material power. HIV aid (*msaada*) that came to Kibera through support groups resurrected PLHIV who were bedridden and provided material relief. For PLHIV, food was equally as important as ARVs in improving their health and prolonging their lives. Some PLHIV economically benefitted from allowances paid for home-based care services. The transport reimbursement provided (including among KNH groups) was very valuable to PLHIV, as it provided them with food and rent. *Msaada* and jobs were very important in strengthening 'living positively' of many PLHIV in low-income settings. Without *msaada* lives would have been worse. Groups were therefore a profitable enterprise for HIV moguls and NGOs, and a survival strategy to PLHIV who did not have an income and familial social support. In the post-treatment era, *msaada* has drastically declined; still, participating in support groups gives PLHIV agency to demand *msaada* when it appears, and to participate in rare advocacy activities, for which they are paid transport allowances.

Social implications

The decision to participate in support groups has social implications, which include acceptance of a new identity, hope and change in relationships. The most fundamental social implication of support groups is hope. HIV-positive diagnosis and the experience with social death motivated PLHIV to want to meet with other PLHIV. In support groups they learn they are not alone. Groups generated a sense of belonging, identity, and connectedness and gave

meaning to lives (Heyer et al., 2010; Liamputtong et al., 2009; Visser et al., 2005; Kalichman et al., 2006; T. Nguyen, 2005; Van Devanter, 2000; Jackson, 2000; Tsisis, 2000). Social implication had a spill over effect on challenging stigma, treatment adherence, social support, and rebuilding social lives. Most important, social contact with other PLHIV can be very instrumental in making outstanding individual and collective resolutions on coping with HIV and responding to their essential needs and desires such as survival, sexuality, reproduction and human rights.

Social support implications

Familial social support remains important to PLHIV (De Klerk, 2011; Iwelunmor et al., 2008; Brown et al., 2010). Where social support from the family or kin is lacking (De Klerk, 2011; Mattes, 2012; Dilger, 2006; Setel, 1999), support groups play a crucial role in providing social support (feeding, access to health services, and treatment adherence). It plays a supplementary but significant role (psychosocial/emotional and informational) where familial support is available. Furthermore, it has led to the adoption of coping skills. In the post-treatment era, support groups challenge families to take up the social support role (mainly nursing care, and financial support during illness) that had reverted back to kin, while community-based organizations act as watchdogs ensuring that kin provide social support.

However, in absence of social support care and support from kin, for instance in the case of MSM sex workers who have cut off links to their kin, under the notion of my brother's keeper, support groups remain a viable source of social support, providing nursing care, offsetting hospital bills, and encouraging access to treatment and treatment adherence.

Limitations of support groups

Practicalities of support groups can be fragile. While these groups hold the potentially transformative power of the individual, they can also disappoint. This study shows that support groups can be a source of psychological distress, social alienation, tensions, contestations, and conflict. First, while information was essential to adopting coping skills, the same information was also a source of psychological stress. Some of the prompted 'Positive living' messages and HIV information brought about anxiety and stress. 'Positive living' messaging – such as following a balanced diet where hardly a meal is affordable, using condoms or PMTCT to prevent transmitting HIV – and the failure of support groups to

meet individual expectations and desires had detrimental psychological implications. Inability to afford prescribed foods or generally a lack of basic practical needs brought about psychological stress, just as learning about side effects of ARVs and the meaning of the CD4 count was a source of psychological stress for those who were not on ARVs and for those whose CD4 count did not improve as expected.

Economic empowerment was not donors' and other development partners' main intent in Kenya, unlike the case of Vietnam where economic empowerment was apparent among self-help group members (Oosterhoff, 2008); the *msaada* in Kenya was but a short-term relief. Massive HIV funding was a source of tensions and conflicts. It brought about competition among PLHIV moguls, and while calling for inclusivity and economic empowerment of PLHIV, support groups and PLHIV led organizations had to compete with other NGOs to access earmarked HIV funding. The uneven economic benefits among PLHIV from the HIV funding bred tensions and conflicts, inclusions and exclusions. Save for the moguls, PLHIV groups fared poorly in competing for HIV funding.

While HIV treatment invigorates lives and HIV funding is drying up, this study shows that the majority of study participants in low-income settings continue to struggle economically, as found elsewhere (Le Marcis, 2012). Support groups were seen as inspirers of income-generating activities, but without funding and training, support groups were not able to deal with economic or material needs. Income-generating activities – merry-go-rounds, groups saving and loans, and bead making – seem an illusion as these initiatives did little toward the economic emancipation of PLHIV. This can lead to a backlash in adopting coping skills, as PLHIV need money for clinical care (side effects and opportunistic infections), transportation to HIV care and treatment centers, and food or dietary recommendations (Hardon et al., 2007; Whyte et al., 2004). Rather table banking creates tensions and conflicts that strain social relations.

Lack of skills to provide psychological care and support made support group space a disappointment for some. Further, the exclusions based on competition for HIV funding, ethnicity, and class created isolation and feelings of dejection within support groups. This resulted in dropout or social alienation by the very group that promised to reduce social isolation.

Conclusion

In conclusion, in over three decades we have witnessed a near collapse of emerging HIV support group systems, as once well-funded community-based initiatives have become dormant in the wake of a global economic crisis that has led to widespread disinvestment in HIV programming or the refocusing of interventions. Because of the lack of a clearly defined mandate, the groups are in a flux and so is HIV biosociality. Support groups resiliently change their objectives and activities to deal with this flux.

The fact that health facilities/providers/biomedical interventions and families recognize and refer PLHIV to these groups, shows that these groups offer what families or consultation rooms cannot offer. These groups are not a simple replacement of the traditional care and support system – they are psychological, socio-reintegrating, hope-propelling, stigma-fighting spaces that also provide emotional healing, love, acceptability, appreciation and respect. As biosocial and bio-value spaces, the groups are a life-transition space and provide a foundation for coping with HIV, and therefore play an instrumental role in HIV prevention and treatment adherence. The groups' achievements are manifest throughout the history of HIV in Kenya, but mainly during the treatment era and beyond. As PLHIV live longer, groups are redefined to attend to emergent issues, and often follow the global waves or development partners and group leaders or owners.

However, choosing to celebrate the positive implications of HIV support groups does not overlook the flip side. As HIV landscape and lives of PLHIV change, so have the meanings PLHIV support groups in ways that affect their health, human rights, and economic, social, sexual and reproductive lives. Support groups did certain things but not others. Some things clearly exceeded expectations and definition of HIV support group discourse; other expectations were simply met but not others. An archipelago of support groups provided PLHIV with varied logics of care and support. These groups, to a certain extent, are potentially injurious- a source of psychological stress, resentments, conflicts, tensions, and social alienation or exclusion. Still, even though PLHIV may not have all their expectations, interests, or desires met and therefore may disappoint, support groups make an essential contribution to the lives of PLHIV who participate in them. City-hopping from one support group to another somehow mitigates limitations. In the presence or absence of the traditional care and support system, support groups remain a very important part of the HIV

response in Kenya. Understanding the individual in a support group is important to understanding the care and support logics of these groups.

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SUMMARY

How would the lives of people living with HIV (PLHIV) in Kenya have gone on without the contribution of HIV Support Groups fighting stigma and discrimination, and providing related care and support? 'My Brother's Keeper' is about people living with HIV caring and supporting each other. Since the discovery of HIV/AIDS in 1980s HIV Support Groups have been a multi-faced phenomenon in Kenya's HIV mitigation landscape. The main aim of studying HIV support groups is to examine how HIV transforms care and social support systems over the last three decades. It explores examines relationships between individual members and the HIV support group structure, specifically, over time, it explores how social relations are created, shaped, and redefined around HIV-positive status.

Since the first diagnosis of HIV/AIDS in 1980s, living with HIV is a frustrating, painful and complex experience: it unsettles the physical, economic, cultural, and social wellbeing of a person. HIV-positive status comes with enormous psychological and emotional consequences. For most PLHIV, significant mental work is required to adjust to the new status. Although effective antiretroviral treatment has allowed many PLHIVs to live longer, HIV chronicity means many of them have to contend with lifelong care and support. HIV can expand the social, psychological, and economic burdens of PLHIV. Chronicity of HIV also means shifting needs and organization of care and support from the government, formal health care system and communities. A strong social support system is one of the most important resources for coping with HIV condition (Van Buuren et al., 1992; Rodgers, 1995). The HIV support group, organized in communities and health facilities, is a critical partner in the fight against HIV.

Most scholarships have documented the value of support groups generally focused on only one group at a particular moment in time. This isolated and static approach make a single story of support groups, and prevents us from understanding the ways that support groups have changed over time in relation to the needs of individual PLHIV, biomedical advancement, donor-demands and global political economies. To explore the contribution of HIV support groups in HIV response trajectory, this thesis uses the lens onto four distinct junctures: pre-treatment, HIV crisis, treatment and end of HIV crisis, and beyond HIV crisis. Support groups, the research shows, assume vital contributions in coping with HIV through various logics of care and support for PLHIV evolving over time. I also argue that the groups are also spaces where the interests of various actors converge, and hold a significant contribution in HIV interventions. While support groups are seen by PLHIV as a space of hope, biomedical interventionists tend to define this space as a system supplementary to medical care provision, and determine the content of care and success in that context. In this context, HIV support group is a space where lives of PLHIV are being re-made and closely scrutinized and a forum for offering the HIV continuum of care

The story of Joseph Jalang'o sets stage for exploring the biosocial relations, engagement of various players, logics of care and support, and relationships that PLHIVs have with support groups. It shows opportunities and disillusionments, and how the groups are positioned by different actors to meet the shifting care and support

needs of PLHIV over time. For this study, I draw attention to different models of HIV support groups: community-based, health facility-based and organic support group models.

Chapter one of this thesis describes the methodology. I followed nine distinct support groups over a two-year period (2011–2012) in Nairobi, the capital city of Kenya, which has a relatively high HIV prevalence in the country. Specific study sites included Kenyatta National Hospital, Kibera informal settlements and River road area in Nairobi's central business district. The Kenyatta National Hospital's facility-based groups included adults, prevention of mother-to-child transmission (PMTCT) clients, youth, discordant couples, and an exclusive men sex therapy group. Community-based groups included three mixed-adults groups from Kibera informal settlements, and Freedom Corner - a group of male sex workers from the backstreets of Nairobi's central business district. Each group was unique in their own right. I triangulated the sources of information and ethnographic data gathering techniques. The chapter also provide insights into negotiating ethical and social licenses on sensitive topics.

Grounded upon medical anthropology and biosocial relations, the study explores a number of support groups over time thus allowing me, first, to avoid a single-story danger, and second to avoid the tendency of disregarding the history of the development of support groups. In so doing, the study, in chapter two (theorizing HIV support groups) sheds light on the concept of biosocial, HIV support groups, care and support. It also looks at the engagements of different players in support group arena, and ways in which PLHIV relate with and make meaning of the support group space.

There are three distinct eras in HIV support groups' trajectory: pre-treatment, HIV crisis, end of crisis and beyond crisis. Chapter three and four provides a historical perspective of the development of HIV support groups. Chapter three focuses on the emergence of the first HIV support groups during pre-treatment time when HIV treatment was too expensive in Kenya. I draw on interviews with the legend HIV activists, and chief executive officers and long serving staff of the HIV NGOs, and media reviews. My study shows the ambivalence HIV response by the government resulting in the failure to protect and promote the healthy wellbeing of its citizens and prevent acute stigma. During this time, I demonstrate how care and support moves from families to emerging HIV support groups. In these groups, people with HIV and AIDS become both providers and recipients of psychosocial/compassionate support through sharing of experiences, battling self-stigma and acquiring HIV-related information. I demonstrate how the objectives of support groups and HIV identities are fluid as groups interact with outside contacts. I show how different logics of care and support emerge. I discuss how commercialization of individual HIV-positive identity for monetary gain, and competition for control of funding resources facilitated the emergence of a local economy of HIV support groups, and clouded the objectives and meanings of support groups resulting in inequality, tensions and discord. I show how while this development challenged the identities and intentions of most NGOs/groups, the role of these groups did not wane. They remained steadfast in putting a face to HIV, educating communities

and fighting stigma and discrimination. In health facilities, support groups were crucial in psychosocial support.

In chapter four I continue to explore the development of HIV support groups at a time of HIV crisis and the end of HIV crisis (1999-2009). The period 1999-2002 was the height and the end of the national disaster marked by high mortality and morbidity, heightened stigma, and weakened familial social support. I discuss how HIV/AIDS incapacitated people's physical and social wellbeing yet there was a dire need for nursing care as well as material and psychological care and support. I demonstrate how support groups expanded in communities offering psychosocial and material care and support. I describe the national level norms, among others, multi-sectoral response and the inclusion of PLHIV in the implementation of HIV interventions coinciding with UNAIDS campaign for inclusivity and the global inclusion strategy known commonly as the Greater Involvement of People with AIDS (GIPA) increased HIV funding and other material support in the communities and the effects on HIV support groups' objectives and structure. I also trace the emergence of support groups in health facilities (in Mbagathi and Kenyatta national hospitals) mainly focused on psychosocial support. The end of HIV crisis (2003-2009) marks yet another milestone in the HIV response trajectory as well as HIV support groups' landscape: a time of treatment accompanied by lucrative resources and proliferation of players. Lucrative resources and treatment expands a local economy of NGOs, CBOs and HIV support groups. In Kibera community, logics of care and support manifests in form of practical needs, nursing care and economic opportunities. I show how through their home-based care, support groups rejuvenated people with AIDS who were bedridden and abandoned. I analyse how desire for support (*msaada*) material gains (in the form of money, food, school fees and clothing) that came through the support groups twisted the meaning of care and support, and destabilized psychosocial support. As support (*msaada*) came through groups, they quickly transformed into material outfits. I also show the entry and effect of materialization of support groups in Kenyatta National hospital. The study shows multiple support group registration and an accelerated *city-hoppa* hoping various care and support.

Chapter four ends with an introduction of yet another critical development in the history of HIV and HIV support groups - 'beyond' HIV crisis (the year 2009 and beyond). Here, HIV prevalence is reduced but to unacceptable level of 5.6 percent. Donors demand for evidence-based strategies to halt new infections and increase access to HIV treatment. This demand coincided with the Kenya HIV Prevention Response and Modes of Transmission epidemiological study that revealed concentrated epidemics among most-at-risk populations. This changed attention and funding to 'key populations', among them men who have sex with men (MSM) and sex workers. Refocus on key population concedes with global activism for homosexual human rights. Redirection of funding to key populations destabilizes the hype of the support groups. A good number of HIV groups transformed into income-generating groups. Some became dormant only to emerge during HIV treatment advocacy activities. Some of the PLHIV on treatment resumed their economic activities. Despite this development, due to high food intake,

HIV syndemics and stigma, they are struggling with practical needs. Only a few PLHIV-led NGOs and community-based organizations transformed from being receivers to providers of health by establishing health facilities to continue attracting donor funding. I show how the Kenyatta National hospital's support groups become hypermedicalized and expand in numbers promoting HIV prevention and treatment through living positively messaging while overlooking the much needed practical needs, especially food. Even within this context, support groups expand in KNH as they diminish visibility in communities.

Chapter 5 of this thesis centred on difficult positions that PLHIV in need of familial care and support finds themselves. I demonstrate how care and support needs of PLHIV in Kibera were not met by families at a time when these activities were re-directed to families. Beyond HIV crisis, stigma denies PLHIV care and support from families and the general society even as a few active support groups and other community-based organizations assumed a watchdog role. In chapter six and seven, using case studies of an exclusive male sex therapy groups and organic male sex workers who have sex with men respectively, I demonstrate how personal needs shape biosocial relations. Using different cases in chapter six I analyse sexual and reproduction logics of care and support are employed in addressing sexual issues of men living with HIV on antiretroviral treatment. In chapter seven I use a case study of an organic support group, Freedom corner, for male sex workers who have sex with men to demonstrate the critical role of Freedom corner support groups in providing a more comprehensive care and support to one another that is unrecognizable by NGOs targeting HIV interventions. This case show survival needs of male sex workers and human rights issues shape biosocial relations.

Overall, this thesis demonstrates the critical role of HIV support groups in lives of PLHIV and HIV response. Support groups brought the necessary visibility to HIV and played a critical role providing care and support for PLHIV. These groups are not a simple replacement of the traditional care and support system – they are psychological, socio-reintegrating, hope-propelling, stigma-fighting spaces that also provide emotional healing, love, acceptability, appreciation and respect. They also address sexual issues that cannot be handled by relatives. As biosocial and bio-value spaces, the groups are life-changing spaces and provide a foundation for coping with HIV. As biomedical innovations and interventions, they have implications in HIV prevention, treatment adherence, and overall health of individuals. Social implications of participation in support groups include acceptance of a new identity, hope, fighting stigma, and change in relationships. Economic implications remained an illusion to many while tremendously changed the fortunes of a few, thus support groups produced opportunities as well as huge economic inequalities. Support groups mitigated myth and misconceptions, denial, fears of side effects, isolation, psychological stress, and help PLHIVs to cope. However, practicalities of support groups can be fragile. While these groups hold the potentially transformative power of the individual, they can also disappoint. They have limitations that compromise the relationship with the individual challenging the concept of my brother's keeper. They are a source of inequalities and

tensions. Where support groups fall short of responding to such needs and desires, members drop out or hop from group to group in search of fulfilment. Despite the shortcomings, support groups are instrumental in HIV interventions.

SAMENVATTING

Hoe zouden de levens van PLHIV ('People living with HIV') in Kenia verlopen zonder de bijdrage van HIV-steungroepen die stigma en discriminatie bestrijden en HIV-gerelateerde informatie verstrekken? 'My Brother's Keeper' draait om mensen die met HIV leven en elkaar verzorgen en ondersteunen. HIV- steungroepen zijn een fenomeen met meerdere aspecten in het Keniaanse HIV-bestrijdings-landschap. Het hoofddoel van deze studie naar HIV-hulporganisaties is te onderzoeken hoe HIV de zorgsystemen en de systemen van sociale steun de afgelopen drie decennia heeft doen veranderen. De studie onderzoekt de relaties tussen individuele leden en de HIV-hulporganisatiestructuur, in het bijzonder hoe sociale relaties rondom de HIV-positief-status in de loop der tijd gecreëerd, gevormd en opnieuw gedefinieerd worden.

Sinds de ontdekking van HIV/AIDS in de jaren tachtig is het leven met HIV een frustrerende, pijnlijke en complexe ervaring: het verstoort het fysieke, economische, culturele en sociale welzijn van een persoon. De HIV-positief-status komt met enorme psychologische en emotionele gevolgen. Voor de meeste PLHIV is flinke mentale inspanning nodig om zich aan te passen aan de nieuwe status. Hoewel effectieve antiretrovirale behandeling veel PLHIV een langer leven schenkt, betekent de chroniciteit van HIV dat veel van hen zijn gebonden aan levenslange zorg en ondersteuning. HIV kan de sociale, psychologische en economische lasten van PLHIV verzwaren. De chroniciteit van HIV heeft ook de nodige implicaties wat betreft de behoeften en de organisatie van zorg en ondersteuning van de overheid, het formele gezondheidszorgsysteem en gemeenschappen. Een sterk sociaal ondersteunend systeem is een van de belangrijkste middelen om met HIV om te gaan (Van Buuren et al., 1992; Rodgers, 1995). De HIV-hulporganisatie, georganiseerd in gemeenschappen en gezondheidsfaciliteiten, is een belangrijke partner in de strijd tegen HIV.

De meeste onderzoeken die de waarde van hulporganisaties hebben vastgelegd richtten zich op één groep op één bepaald moment. Deze geïsoleerde en statische aanpak maakt één enkel verhaal van steungroepen en verhindert ons te begrijpen op welke manieren steungroepen in de loop der tijd zijn veranderd in relatie tot de behoeften van individuele PLHIV, biomedische vooruitgang, donor-eisen en mondiale politieke economieën. Om de bijdrage van HIV-ondersteunende groepen in het HIV-respons-traject te onderzoeken, richt dit proefschrift de lens op vier verschillende punten: de pre-behandeling, de HIV-crisis, de behandeling en het einde van de HIV-crisis en het tijdperk na de HIV-crisis. Het onderzoek laat zien dat steungroepen belangrijke bijdragen leveren aan de omgang met HIV aan de hand van verschillende logica van zorg en ondersteuning voor PLHIV die in de loop van de tijd evolueren. Ik beargumenteer ook dat de groepen bovendien *ruimte* bieden waar de belangen van verschillende actoren samen komen en een belangrijke bijdrage leveren aan HIV-interventies. Terwijl steungroepen door PLHIV als een *ruimte* van hoop worden gezien, hebben biomedische interventionisten de neiging deze *ruimte* te definiëren als een aanvullend systeem voor medische zorg, en de inhoud van zorg en succes in die context te bepalen. In

deze context is de HIV-steungroep een *ruimte* waarin de levens van PLHIV opnieuw gevormd en nauwkeurig onderzocht worden, evenals een forum voor het aanbieden van het HIV-zorg-continuüm.

Het verhaal van Joseph Jalang'o geeft een achtergrond voor het verkennen van de biosociale relaties, de betrokkenheid van verschillende actoren, de logica van zorg en ondersteuning en de relaties die PLHIV hebben met steungroepen. Het toont kansen en teleurstellingen en hoe de groepen door verschillende actoren worden gepositioneerd om tegemoet te komen aan de veranderende zorg- en steun-behoefte van PLHIV door de tijd heen. In dit onderzoek vestig ik de aandacht op verschillende modellen van HIV-steungroepen: 'community-based', 'health facility-based' en organische steungroep-modellen.

Hoofdstuk een van dit proefschrift beschrijft de methodologie. Ik volgde negen verschillende steungroepen over een periode van twee jaar (2011-2012) in Nairobi, de hoofdstad van Kenia, welke vergeleken met de rest van het land een relatief hoge prevalentie van HIV kent. Specifieke onderzoekslocaties zijn onder andere het Kenyatta National Hospital (KNH), informele nederzettingen in Kibera en de River Road Area in het centrale zakendistrict van Nairobi. De groepen uit Kenyatta National Hospital waren onder meer volwassenen, cliënten van moeder-op-kind-overdracht-preventie (prevention of mother-to-child transmission, PMTCT), jongeren, partners met conflicten en een exclusieve sekstherapiegroep voor mannen. Onder de community-based-groepen waren drie gemengde volwassenen groepen uit de informele nederzettingen van Kibera en Freedom Corner –een groep mannelijke sekswerkers uit de achterbuurt van het centrale zakendistrict van Nairobi. Elke groep was uniek op haar eigen manier. Ik heb de informatiebronnen en ethnografische dataverzoekstechnieken getrianguleerd. Het in kaart brengen van de steungroepen, participerende observatie, gesprekken, diepte-interviews, focusgroep-besprekingen, levensgeschiedenissen en wandel-sessies waren de primaire dataverzamelingstechnieken. Media-reviews, een secundaire data-verzamelingmethode, geven de hoogtepunten van de verslaggeving over stigma weer, welke teruggaat tot de jaren negentig. PLHIV die deelnemen aan steungroepen en informanten (vertegenwoordigers van overheid en ontwikkelingspartners, leiders van PLHIV-geleide NGOs, CBOs en steungroepen, *peer educators* en HIV-activisten) waren van essentieel belang voor deze studie. Ik bied ook inzicht in het onderhandelen van ethische en sociale licenties over gevoelige onderwerpen.

Gebaseerd op de antropologie over medische en biosociale relaties, onderzoekt deze studie een aantal steungroepen in de loop van de tijd, waardoor ik in de eerste plaats het gevaar van een eenzijdig verhaal kan vermijden, evenals de neiging om de geschiedenis van de ontwikkeling van steungroepen te negeren. Daarbij werpt de studie in hoofdstuk twee (theorizing HIV steungroepen) licht op het concept van biosociale, HIV-steungroepen, zorg en ondersteuning. Het kijkt ook naar de betrokkenheid van verschillende spelers in de steungroep-arena, en op welke manieren PLHIV in verband staan met en betekenis geven aan de steungroep-ruimte.

Er zijn drie verschillende tijdperken in het traject van de HIV-steungroepen: pre-behandeling, de HIV crisis, het einde van de crisis en de periode na de crisis. Hoofdstukken drie en vier geven een historisch perspectief op de ontwikkeling van HIV-steungroepen. Hoofdstuk drie richt zich op de opkomst van de eerste HIV-steungroepen tijdens de pre-

behandeling-tijd, toen HIV-behandelingen te duur waren in Kenia. Ik put uit interviews met gevestigde HIV-activisten, directie- en ander personeel van HIV-NGO's met een lange staat van dienst, en media reviews. Mijn onderzoek toont de ambivalentie van HIV-reacties van de overheid, waardoor zij er niet in slaagt de gezondheid en het welzijn van haar burgers te beschermen en bevorderen en stigmatisering te voorkomen. Ik laat zien hoe in deze periode zorg en ondersteuning verplaatsten van families naar de opkomende HIV-support-groepen. In deze groepen worden mensen met HIV en AIDS zowel de aanbieders als ontvangers van psychosociale/begripvolle steun door het delen van ervaringen, het strijden met zelf-stigma en het verkrijgen van HIV-gerelateerde informatie. Ik laat zien hoe de doelstellingen van steungroepen en HIV-identiteiten vloeibaar zijn, omdat groepen in interactie staan met externe contacten. Ik laat zien hoe verschillende logica van zorg en ondersteuning ontstaan. Ik bespreek hoe de commercialisering van individuele HIV-positieve identiteit voor monetaire winst en concurrentiestrijd over controle op financiële middelen de opkomst van een lokale economie van HIV-steungroepen faciliteerden en de doelstellingen en betekenissen van steungroepen overschaduwden, waardoor ongelijkheid, spanningen en conflict ontstaan. Ik laat zien hoe deze ontwikkeling de rol van deze groepen niet heeft verminderd, hoewel het de identiteiten en intenties van de meeste NGOs/groepen heeft uitgedaagd. Zij bleven standvastig in hun intentie om HIV een gezicht te geven, gemeenschappen voor te lichten en stigmatisering en discriminatie te bestrijden. In gezondheidsfaciliteiten waren steungroepen van cruciaal belang bij psychosociale ondersteuning.

In hoofdstuk vier ga ik verder met de ontwikkeling van HIV-steungroepen in een tijd van HIV-crisis en het einde van de HIV-crisis (1999-2009). De periode 1999-2002 omvat de piek en het einde van de nationale ramp, gekenmerkt door veel sterfte en morbiditeit, verhoogd stigma en verzwakte familiale sociale support. Ik bespreek hoe HIV/AIDS het fysieke en sociale welzijn van mensen beïnvloedde, terwijl er een enorme behoefte was aan verpleegzorg, evenals aan materiële en psychologische zorg en ondersteuning. Ik laat zien hoe steungroepen zich uitbreidden in gemeenschappen waar ze psychosociale en materiële zorg en ondersteuning aanboden. Ik beschrijf onder andere de nationale niveaunormen, multi-sectorale respons en het betrekken van PLHIV bij de implementatie van HIV-interventies die samenvallen met de UNAIDS-campagne voor 'inclusivity' en de mondiale 'inclusion'-strategie die algemeen bekend staat als the Greater Involvement of People with AIDS (GIPA). Ik analyseer het effect van verhoogde HIV-financiering en andere materiële steun in de gemeenschappen op de doelstellingen en structuur van de HIV-steungroepen. Ik heb ook de opkomst van steungroepen in gezondheidsfaciliteiten getraceerd (in de nationale ziekenhuizen van Mbagathi en Kenyatta) die vooral gericht was op psychosociale ondersteuning. Ik onderzocht ook het einde van de HIV-crisis (2003-2009), welke nog een andere mijlpaal markeert in het HIV-respons-traject en het landschap van de HIV-steungroepen: een tijd van behandeling die vergezeld ging met lucratieve middelen en de proliferatie van actoren, in het bijzonder HIV-steungroepen. Lucratieve middelen en behandeling deden een lokale economie van NGO's, CBO's en HIV-ondersteunende groepen groeien. In de Kibera-gemeenschap manifesteert logica van zorg en ondersteuning zich in de vorm van praktische behoeften, verpleegkundige zorg en economische mogelijkheden. Ik bespreek hoe steungroepen met hun thuiszorg mensen met AIDS van nieuw elan voorzagen

die voorheen aan het bed gekluisterd en verlaten waren. Ik analyseer hoe het verlangen in de groepen naar materiële winsten de betekenis van zorg en steun verdraaide en psychosociale ondersteuning destabiliseerde. Omdat steun (msaada) in de vorm van geld, eten, schoolkosten en kleding via groepen kwam, veranderden ze snel in materiële uitgiftepunten. Ik bespreek de intrede en het effect van de materialisatie van steungroepen in het Kenyatta National Hospital. De studie laat zien hoe mensen zich bij meerdere steungroepen hebben geregistreerd om te profiteren van steun uit verschillende bronnen.

Hoofdstuk vier eindigt met een introductie van nog een belangrijke ontwikkeling in de geschiedenis van HIV en HIV-ondersteunende groepen - 'voorbij' de HIV-crisis (het jaar 2009 en daarna). Hier is de prevalentie van HIV verminderd, maar tot een nog steeds onaanvaardbaar niveau van 5,6 procent. Donors eisen dat op evidence-based strategieën nieuwe infecties stoppen en de toegang tot HIV-behandelingen vergroten. Deze vraag viel samen met de epidemiologische studie de 'Kenya HIV Prevention Response and Modes of Transmission', die geconcentreerde epidemieën onder populaties met het meeste risico blootlegde. Dit verlegde de aandacht en financiering naar specifieke risicopopulaties, waaronder mannen die seks hebben met mannen (MSM) en sekswerkers. Het verleggen van de focus op risicopopulaties is in lijn met mondiaal activisme voor homoseksuele mensenrechten. De herallocatie van financiering naar belangrijke populaties destabiliseert de hype van de steungroepen. Een aanzienlijk aantal HIV-groepen veranderden in inkomensgenererende groepen. Sommigen werden inactief en kwamen alleen tijdens de promotie van HIV-behandelingen opnieuw op. Een deel van de PLHIV in behandeling hervatte hun economische activiteiten. Ondanks deze ontwikkeling worstelden ze door hoge voedselinname, HIV-syndroom en stigma met praktische behoeften. Slechts een paar PLHIV-geleide NGOs en community-based organisaties zijn veranderd van ontvangers naar aanbieders van gezondheidszorg door gezondheidsvoorzieningen op te zetten om donorfinanciering te blijven aantrekken. Ik laat zien hoe de steungroepen van het Kenyatta National Hospital hyper-gemedicaliseerd worden en groeien in aantallen, terwijl ze HIV-preventie en behandeling promoten door positief te leven, maar de broodnodige praktische behoeften, met name voedsel, over het hoofd zien. Zelfs in deze context groeien de steungroepen in KNH, terwijl ze zichtbaar verminderen in gemeenschappen.

Hoofdstuk vijf van dit proefschrift draait om de moeilijke positie waarin PLHIV die zorg nodig hebben van hun familie verkeren. Ik laat zien hoe families niet de zorg en steun boden aan PLHIV in een periode waarin deze activiteiten naar families werden herleid. Voorbij de HIV-crisis zorgt stigma ervoor dat PLHIV geen steun krijgen van familie en de maatschappij in het algemeen, ook al hebben een aantal actieve steungroepen en andere community based organisaties de rol van waakhond aangenomen. In hoofdstuk zes en zeven laat ik aan de hand van case studies naar een exclusieve sextherapiegroep voor mannen en mannelijke sekswerkers zien hoe persoonlijke behoeften biosociale relaties vormgeven. Aan de hand van verschillende cases, analyseer ik in hoofdstuk zes hoe seksuele en reproductieve logica van zorg en support worden gebruikt in het omgaan met seksuele zaken van mannen die leven met HIV en een antiretrovirale behandeling. In hoofdstuk zeven gebruik ik een casestudy van een organisch gevormde steungroep, Freedom Corner, voor mannelijke sekswerkers die seks hebben met mannen, om de belangrijke rol van Freedom Corner steungroepen te laten zien in het bieden van een meeromvattende zorg en support aan elkaar, welke niet wordt herkend

door NGOs die zicht richten op HIV-interventies. Deze case laat zien hoe de overlevingsbehoeften van mannelijke sekswerkers en mensenrechtzaken biosociale relaties vormen.

Al met al laat dit proefschrift de cruciale rol van HIV-steungroepen in het leven van PLHIV en HIV-respons zien. Steungroepen zorgden voor de noodzakelijke zichtbaarheid van HIV en speelden een cruciale rol in de zorg en ondersteuning voor PLHIV. Deze groepen zijn niet simpelweg een vervanging van het traditionele zorg- en supportstelsel - het zijn psychologische, sociaal-herintegrerende, hoopgevende, stigma-bevechtende *ruimtes* die ook emotionele genezing, liefde, acceptatie, waardering en respect bieden. Ze behandelen ook seksuele problemen waarmee familieleden niet helpen. Als biosociale en bio-waarde-*ruimten* bieden de groepen *ruimten* die levens veranderen en een basis verschaffen voor het omgaan met HIV. In de vorm van biomedische innovaties en interventies hebben ze gevolgen voor HIV-preventie, behandeling, en de algemene gezondheid van individuen. Het sociale gevolg van deelname aan ondersteuningsgroepen omvat acceptatie van een nieuwe identiteit, hoop, het bestrijden van stigma en veranderingen in relaties. Economische gevolgen bleven een illusie voor velen, terwijl ze het lot van slechts enkele PLHIV grotendeels veranderden, waardoor steungroepen zowel kansen als enorme economische ongelijkheid veroorzaken. Steungroepen verzachten mythe en misvattingen, ontkenning, angst voor bijwerkingen, isolatie, psychologische stress en helpen PLHIV met hun situatie om te gaan. De praktische eigenschappen van steungroepen kunnen echter broos zijn. Terwijl deze groepen de in potentie veranderende kracht van het individu omvatten, kunnen ze ook teleurstellen. Ze hebben beperkingen die de relatie met het individu in gevaar brengen, waarbij het concept van 'My Brother's Keeper' ter discussie wordt gesteld. Als de steungroepen er niet in slagen te reageren op zulke behoeften en verlangens, vertrekken leden of stappen zij van groep naar groep over op zoek naar vervulling van hun behoeften. Ondanks de tekortkomingen zijn steungroepen instrumenteel in HIV-interventies.